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FAMILIES DESIGNED THROUGH ART: EXPLORING EMBODIED EXPERIENCE AND CONCEPTION DISCLOSURE BASED ON SEXUAL IDENTITY

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ABSTRACT

This dissertation uses data from an original online survey including a diverse sample of individuals across different sexual and gender identities, who have given birth to at least one child successfully conceived using ART (N=114). I use a mix of qualitative and quantitative techniques to examine parents' experience undergoing fertility treatment as well as conception disclosure. My research has two overall research objectives: first, to explore and analyze variations in the experience of fertility treatment process based on sexual identity; second, to examine differences in attitudes towards conception disclosure as well as disclosure importance and behaviors based on sexual identity. I engage mostly a conflict, feminist and medical consumerism frameworks to discuss individual experience and behavior within the medical encounter for fertility treatment. I also use symbolic interactionism and communication privacy management theory frameworks to gain insight on conception disclosure processes.

My findings highlight that some individuals felt the process of ART was depersonalized, regimented, and homogenized, which left them feeling disempowered and disaffected. These participants responded in multiple ways by empowering themselves through research about different options, approaches, and techniques; they questioned physician expertise; demanded inclusion in determining treatment plans; and at times, decided to discontinue their service relationships. The discontinuation of service is an important form of resistance for fertility patients who felt marginalized during the process or minimized to their biological and reproductive capacity. In this way, my research shows that fertility treatment is not exempt from medical consumerist behaviors. Individuals are agentic medical consumers who act as medical associates during the process of fertility treatment. Participants' retelling of their experiences provides counter narratives to the patient-as-passive-recipient model of healthcare and responds

to some feminist concerns. The overall experience during the treatment process did not differ based on sexual identity, however sexual minority persons had some unique experiences stemming from heteronormative structures.

My data also show that parents were more inclined to disclose to family, close friends and physicians but practiced more restraint when sharing with other persons. When it comes to conception disclosure to the child, among other reasons, parents felt it was important to demonstrate to the child they were wanted and to transfer aspects of the child medical history. They also thought disclosure was necessary to fight shame. In this dissertation, I argue that individuals make decisions about conception disclosure in response to social norms. More specifically, I make the claim that parents are engaged in subversive disclosure to disrupt dominant opinions about assisted reproduction as unnatural and children conceived through ART as "synthetic" or different. Thus, my research recognizes that individuals are embedded in social systems that ultimately influence their decisions concerning disclosure. I observed nuanced differences based on sexual identity; which lead me to argue that heterosexual identified persons were more likely to restrict conception disclosure in comparison to sexual minority persons.

Based on conception disclosure timing strategies I categorize persons as intentional early initiators or opportunistic seguers. I also grouped participates into two categories based on their conversational approach to disclosure: those who are straight talkers and those engaged in creative dialogue. Still conception disclosure can be overwhelming, leading some parents to create their own patchwork, hybrid approach. Sexual minority parents' disclosure practice differed from heterosexual identified persons in one key way; specifically, sexual minority persons constructed the content to emphasize different family structures and the way families are created.

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As I reflect on my journey, I am reminded of an old gem by Henry Wadsworth Longfellow – "The heights by great men reached and kept were not attained by sudden flight, but they, while their companions slept, were toiling upward in the night." Though the road may have been rocky, arduous, and long, there were many smiling faces, encouraging words, sympathetic hugs, and high fives that made the process bearable. First, I thank my parents for all their hard work, dedication, and encouragement. I dedicate this dissertation to my Dad, the truest autodidact I know, who himself has limited formal education but relentlessly supported my academic pursuits. A most sincere gratitude to my Mom, for her continued support and for always assuring me that *'where there is a will, there is a way.'* To my life partner Carl, there are no words to express my appreciation for the care, sacrifice, love, commitment, and encouragement you have given over the years. A heartfelt thank you to all my family members who helped me make the transition to and from Syracuse as well as to those who checked-in on occasion to ensure I was not buried by snow.

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CHAPTER 1

INTRODUCTION & BACKGROUND

I. INTRODUCTION

The advancement of Assisted Reproductive Technology (ART) since the latter part of the 20th century has changed the way we think about sex, reproduction, and parenthood. Reproductive technologies, such as in vitro fertilization (IVF), eliminate the requirement for sexual intercourse and even an opposite sex partner to make reproduction and parenthood possible. Fertility treatments originally conceived of for persons experiencing medical infertility are now viable options for individuals with social infertility.[1,2] According to Peterson (2005), "[t]echnologies such as IVF and other ARTs inevitably provide normative challenges as they widen the scope of reproductive options and contest the traditional notions of motherhood, pregnancy, and childbirth" (p.280). Steiner (2013) refers to the changes brought about by surrogacy, and I add more broadly reproductive technologies, as the "transmogrification of pregnancy and parenthood" – a radical turn "from natural conception" (p.26).

At the current intersection of biology, medicine, and technology, the three essential elements of human reproduction - sperm, egg, and womb - can be any one or combination of owned, sold, purchased, or leased. This has opened up an entire field of inquiry concerning the commodification of genetic material, bioethics, pathways to parenthood, and diverse family forms (see for e.g. Almeling 2011; Gamson 2015; Steiner 2013). Although these medical, scientific, and technological developments are notable, they have far outdistanced social and legislative change, which has resulted in "structural lag" (Riley et al 1994). Specifically,

[1] I use medical infertility to refer to women who meet the medical definition of infertility which is the inability to conceive for a period of 12 months or to carry a child to term. I use social infertility to refer to women challenged with conceiving naturally due to the absence of a male partner who have also used ART as a pathway to parenthood.
[2] Boivin et al. (2001) uses the term to cover lesbian couples and single women without partners.

individuals who utilize these reproductive possibilities to build family are vulnerable to stigma and discrimination from which the law currently provides no protection. Relevant to the field of sociology is that these biomedical technologies and processes do not provide equal opportunity structures for every person. For example, varying social identities influence both choice and access to reproductive technologies to include income, race, marital status, sexual identity and gender identity (Bell 2009, 2010; Kessler et al 2013).

In this chapter, I present an overview of my dissertation project; highlighting some macro-level data along with some structural factors that impact access to and use of ART. I also outline some publicly available anecdotal accounts of peoples' experiences to set the stage for my own data and to demonstrate the significance of my research. I also provide a chapter by chapter overview of the research questions and analytical strategies used to make sense of the data. This chapter, along with Chapters 2 and 3, provide the foundation for my dissertation project as well as the analytical chapters that follow.

II. SPECIFIC AIMS & OBJECTIVES

Within the last two decades, a burgeoning body of literature has examined the social construction of infertility, experiences of infertility, and access to fertility treatment (Bell 2009, 2010; Jennings 2010; Williams 1997). Some feminist scholars and medical sociologists have discussed the growth of the biotechnology industry, medical hegemony, the use of reproductive technology, as well as the resultant and continuing loss of control that women experience over their own bodies (Greil et al. 2010; Lorber 2000; Strickler 1992). Generally, studies have focused separately on the experience of heterosexual women or couples who suffer with infertility and, to a lesser extent, lesbian women who use donor sperm or gay men who choose surrogacy (Bergman et al. 2010; Greil et al. 2010; Mamo 2007). Due mostly to social norms and

legislative restrictions, the latter studies tend to emphasize how same-sex families fair in comparison to the standard two-parent heterosexual family. Few scholars have compared decision-making processes, experiences, and information management with respect to use of reproductive technology across sociodemographic groups.

My research surveys a diverse sample of women who identify as heterosexual, lesbian, gay or queer and have used reproductive technologies to achieve pregnancy (N=114). The survey covers a wide cross section of questions to include the desire for parenthood; pregnancy and reproductive history; experience of fertility treatment and conception disclosure among the population of interest. Overall, the research project examines differences on the basis of sexuality among women who had a least one child with the use of ART. The overall research objectives are as follows:

- Objective#1: Explore and analyze variations in the experience of fertility treatment process based on sexual identity.
- Objective#2: Examine the importance of conception disclosure to children as well as differences in attitudes towards conception disclosure and disclosure behaviors based on sexual identity.

Each chapter of this dissertation outlines further details about the specific guiding research questions.

This study examines the experience of ART and the management of stigmatized identities within a social and cultural context where a normative family structure is valued and where systems (socio-political, legal, and economic) maintain the status quo by oppressing alternative and seemingly unnatural family forms. I conducted primary data collection online to explore and analyze variations in decision making, experiences, and discourse around ART based on

sexuality, moving beyond normative users diagnosed as medically infertile. This study pays attention to individuals who have been historically excluded from medically assisted conception research because they do not align with the conventions of human reproduction within heterosexual marriage structures and/or because they identify as lesbian, gay, or queer.

I hypothesized that decisions, experiences, and discourses around assisted conception would vary based on sexuality. Based on the literature reviewed in Chapter 2, I theorized that individuals whose sexual identity fits a more normative prescription (e.g., heterosexual cisgender women) are more likely to gain access and have positive experiences within the market for reproductive materials and services. However, despite these positive experiences, I expected that heterosexual identified parents would be more likely to conceal their mode of conception. I anticipated that sexual minority women, on the other hand, would have more negative fertility treatment experiences. I, therefore, hypothesized that sexual minority women would be more likely to disclose their mode of conception to bring light to their negative treatment experience and as a strategy to help the child to understand their family structure and the complexity of their circumstances (e.g., involvement of a donor) within a larger social, legal, and political context.

This research provides the advantage of exploring the multiple facets of reproduction among those who are unable to conceive naturally. Research questions and the survey instrument, which strategically progresses from the desire to become parents through conception, birth, and disclosure, set the groundwork to fill gaps in research pertaining to assisted reproductive technologies as a pathway to parenthood.

III. BACKGROUND

Infertility, which is medically defined as the failure to conceive after one year of unprotected sex, is believed to be a common problem among women in the United States. Based on data from the National Survey on Family Growth (2006-2010), the Centers for Disease

Control (CDC) estimate that about 1.5 million or 6% of married women experience infertility (Chandra et al. 2013). The proportion of women ages 15-44, who have ever used infertility services, has remained at 12% since 2002. Although the actual numbers have declined, the estimated 7.4 million who access infertility treatment is still significant (Chandra et al. 2014). An estimated 85-90% of infertility cases are commonly treated with drugs or surgery and less than 3% with the use of ART (Resolve 2015). Data on ART prominently features married couples with infertility issues while less is known about other individuals who utilize these services for reasons other than medical infertility.

ART is a pervasively used nomenclature, yet there is no one understanding or existing monolithic description as evidenced by varying conceptualizations in research, legal documents, and statistical reports. The CDC, for example, employs a definition of ART based on the *Fertility Clinic Success Rate and Certification Act of 1992*. Section 8(1) of the Act defines ART as "all treatments or procedures which include the handling of human oocytes or embryos, including in vitro fertilization, gamete intrafallopian transfer, zygote intrafallopian transfer, and any such other specific technologies as the Secretary may include…" (106 STAT. 3151). Although the Act of 1992 sets a precedence for what should be considered ART, the language unmasks the subjectivity of *how* and *what* is included by placing the power of classification in the hands of an appointed official. The CDC, therefore, uses ART to refer to a class of medical treatment used to handle *both* eggs and sperms outside of the body to establish a pregnancy (Chandra et al. 2014). As a consequence, such procedures as artificial insemination or intrauterine insemination are excluded from their classification. The Society for Assisted Reproductive Technology (SART) uses a similar definition that excludes intrauterine insemination, while the National Infertility Association (also known as Resolve) broadly describes ART as involving "several medical

treatment designed to result in pregnancy" despite listing the same techniques used by the CDC. The Model Act (2008), on the other hand, provides what appears to be a more inclusive framework, defining ART as "any medical or scientific intervention…provided for the purpose of achieving live birth." Pursuant to the Model Act, ART includes assisted reproduction through intrauterine insemination, donor eggs, and donor sperm (American Bar Association 2008). In my dissertation, I accept the more liberal definition of ART as any medical intervention used to accomplish pregnancy. I, therefore, use the term ART interchangeably with other terminologies such as fertility treatment, assisted reproduction, assisted conception, and medically assisted conception.

Estimates based on national surveys suggest that individuals who identify as either lesbian or gay have equal desires to have children, but are less likely to have children compared to heterosexuals. Gates (2013) uses the 2008 and 2010 General Social Survey (GSS) to report that 37% of lesbian, gay, and bisexual identified individuals have had a child. The proportions are similar among transgender individuals (38%) according to the National Transgender Discrimination Survey (Grant et al. 2011). These are significantly less than the proportion of heterosexual individuals who are parents. For example, earlier estimates using the 2002 National Survey on Family Growth (NSFG) found that among women of childbearing age (18-44), 35% of lesbians had given birth compared to 65% of women who identified as heterosexual or bisexual (Gates et al. 2007). The lower likelihood of having children among lesbian and transgender persons can be linked to what Patterson and Riskind (2010) refer to as "logistical barriers," which are due in part to a lack of access or knowledge about different pathways, discriminatory policies concerning adoption and foster care, among other legislative chokeholds (p.329).

Currently, there are no legal restrictions or nondiscrimination policies in the United States pertaining to the use of reproductive technologies. The New York State Task force posits that, “physicians offering assisted reproduction are under no legal or ethical obligation to treat every individual or couple who request their services. Providers also have significant latitude as a result of the exercise of medical judgment” (Stern 2002:540). Ostensibly, an individual can be refused treatment or potentially ruled ineligible for treatment, thus codified differently under the rubric of medical risk concern. Failure to develop equal opportunity policy with respect to ART, therefore, gives full responsibility to health practitioners who independently calibrate their moral compass with the professional ethical code of conduct.

Efforts to develop an inclusive policy for fertility treatment access are in an embryotic stage. The American Society for Reproductive Medicine (ASRM) (2013) petitions that programs apply the same standards for unmarried, lesbian and gay individuals as they would married heterosexual individuals in light of evidence that children within these family forms are at no greater disadvantage (p.1526). Similarly, the American Psychology Association Council (APA) developed a resolution to end any form of discrimination that deprives any adult the right, privilege, and benefit of having children based on sexual orientation (Paige 2005:19). These guidelines, provided by both ASRM and APA, while commendable, are not enforceable by law. Consequently, groups of people remain vulnerable to discretionary practices by physicians as well as fertility clinic administrators and staff.

One significant factor impeding access for many is the costs associated with fertility treatment. Several developed countries have integrated infertility treatment into national health policies including Australia, Austria, Denmark, Finland, France, Germany, Iceland, The Netherlands, Norway, and Sweden (Jain & Horstein 2005:221). To date, only 15 U.S. states have

passed laws mandating that insurance companies cover infertility treatment - Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and West Virginia (East Coast Health Insurance n.d.). The terms and definition, however, vary across these fifteen states, but mostly reflect very heteronormative notions about reproduction. In more cases than not, fertility challenges are constructed as medical/physiological defects, which therefore makes ART indistinguishable from infertility treatment and in effect precludes individuals limited by social circumstances. Illinois and Massachusetts, for example, require the patient meets the medical definition of infertility, that is, the failure to conceive after a year of unprotected sexual intercourse as well as the inability to sustain a successful pregnancy (East Coast Health Insurance n.d.). Arkansas and Maryland have more prohibitive guidelines, requiring a two-year history of infertility due to medical reasons such as blocked/removed tubes or endometriosis, and unsuccessful attempts through less expensive procedures. Arkansas further stipulates that only the spouse's sperm can be used to fertilize the patient's eggs. Rhode Island also includes marriage as a condition for treatment coverage. Given these differences across states, it is even more apparent that individuals in the United States do not have equal access to ART.

IV. THE MICRO REALITY OF FERTILITY TREATMENT

On September 3, 2015, the National Infertility Association ran a blog post by Jake Anderson on their Facebook page entitled, *"Finding A Fertility Doctor Is Total Hell."* The author Jake and his wife Deborah, established *fertilityiq.com* to document their fertility treatment experience. On the website they stated, *"Undergoing fertility treatment is about hope and bringing life into the world, but the process of finding a fertility doctor is lonely and intimidating, and made more difficult by a lack of credible information."* In the blog post Jake's

remark placed a doctor with the "expertise, resources and comportment" in direct contrast to one who will "abscond with your time, money and hope." In three years, the couple had undergone the process with three different doctors. The first instructed Deborah to leave in her IUD, which later resulted in low follicle counts diagnosed as early menopause and came at a cost of $20,000 dollars plus "3 months of agony." The relationship with the second doctor terminated after a visit to the emergency room because the nurse had misread Deborah's chart, encouraged her to consume a lot of water, which later caused diminished level of sodium in her blood. Three years, two doctors, and a few health scares later, the couple, at the time of the post, was optimistically on to doctor number three. In a feature article, published in June 2016 by the *New York Times*, the couple had conceived naturally and given birth to a baby boy two months prior. Much like this couple's experience, it is not uncommon among fertility patients to undergo several failed procedures that are financially, physically, and emotionally costly.

In a fertility diary post on Motherlode blog dated December 10, 2013, entitled, "My I.V.F. Education," the author Amy Klein discussed receiving a call from the clinic to explain that neither of her eggs from the previous day had fertilized (The New York Times). Reflecting on her experience, she questioned whether being more informed about the process would have resulted in a better outcome. Klein wrote, "We live in an era in which health information is readily available on websites…How much knowledge is really helpful, and how much is about feeling in control in a process in which there is so little?" At first, Klein was opposed to playing the role of a fertility patient, always confronting doctors with a barrage of information on the most recent interventions and switching clinics like another couple with whom they were friends. Following the telephone call, however, she did some internet research and discovered that the clinic could have done a "rescue ICSI" after the failed fertilization and described instantly

regretting her "naiveté." By the time Klein had come by this information the treatment failed, it was too late for the rescue mission and the sums of money for treatment already spent. She wrote, "Next time…I'll also be more educated about my fertility, understand the medicines I'm taking, what my blood tests mean and when my retrieval is timed. It may not make for a pleasant patient, but maybe it will help us have a baby." This anecdotal account raises several questions about the role of self-education and research in the creation of a more active, informed and involved fertility patient. Does the outcome differ based on the patient's level of knowledge and understanding?

Identifying as lesbian, gay, or queer is a salient part of the fertility treatment experience. Issues of heterosexism and overall lack of sensitivity in the treatment of same-sex couples have been documented in some research (see Chapter 2). These issues and many others illustrate the role of medicine as a social institution that structures biological reproduction. An article written by Stephanie Fairyington published in the *New York Times* on November 2015 entitled, "Should Same-Sex Couples Receive Fertility Benefits?" featured the story of a lesbian couple's journey to parenthood. The couple, although paying into an insurance policy that covered fertility treatment, was unable to benefit because they did not meet the insurance policy's medical definition of infertility. The couple believed the policy was based on the premise that "a lesbian could get pregnant by having sex with a man, she just chooses not to" and was thus discriminatory. After 12 months of failed IUIs, reimbursement attempts were rejected because the insurance company claimed that the couple was now a candidate for IVF, which was not covered by the policy. Cost significantly limits access to fertility treatment and even when individuals have insurance they sometimes fail to meet the criteria for coverage. For sexual

minority persons, the hurdles involved to obtain treatment may well explain the lower rates of access.

In a post entitled “Telling your child they’re IVF,” published on July 3, 2014, guest blogger Julia Bateson discussed her desire to tell her daughter she was an “extra-special ‘miracle’ IVF child.” According to Bateson she contacted her daughter’s head teacher to determine whether information on IVF was a part of their sex education curriculum because she “felt that it was important to give balanced information so that all IVF children would feel ‘equal’ to their peers and not odd.” The teacher confirmed that it was not and invited Bateson to assist with improving the syllabus. She further explained that when her daughter was age 10 she began discussions with the help of books about puberty and the body. Months later, she continued that discussion to include reproduction in general and the child’s coming to existence. At this time her husband, also a part of the conversation, explained that they were unable to conceive naturally and needed the help of doctors and nurses. They continued to explain the IVF process and remarked, “But the magical thing for us was that we got to see you under a microscope first before you were put inside mummy.” In a follow-up post, Bateson discussed how important it was to “normalize” IVF so that her daughter would not feel like she was a “freak.” The decision to disclose was collectively made with another couple who had twins through IVF. This shared history forged a bond between the children and helped to make “IVF feel mainstream, more common and ‘normal’.” The parents subsequently decided to disclose to family and friends.

These blog posts, made during the early stages of my research, document and highlight some of the major issues brought to the fore in my study data. These include issues pertaining to: locating a doctor/clinic; expertise and competence; investment in time, money and emotions;

traumatic effects of fertility treatment; importance of self-advocacy and research; experiences based on sexual identity; and disclosure decisions and practice. These select few posts demonstrate both the timeliness and significance of my research and several of the selected quotes highlighted in the chapters of my dissertation reflect very similar experiences.

V. STUDY CONTRIBUTIONS

My research furthers discussion about fertility treatment within the academic sphere and has some theoretical, methodological, substantive, and policy significance. Previous studies that have explored the experience of fertility treatment have focused on clinic continuation and discontinuation; quality of care; and patient satisfaction (Gameiro et al. 2012; Groh and Wagner 2005; Leite et al. 2005). From a sociological perspective, scholars have been concerned with the social construction and medicalization of infertility; access to treatment; and insurance coverage (Bell 2009, 2010; King and Harrington-Meyer 1997). Medical sociologists have also discussed patients' experience within the medical encounter for decades (e.g., Waitzkin 1989). My research substantively contributes to this body of work by examining fertility treatment experience within medical encounters. Scholars have done similar work exploring differences based on race (Bell 2010), however my research explores differences based on sexual identity.

Previous research on conception disclosure has largely been from medical practitioners' perspectives. Scholars have often deployed surveys and focused mainly on the myriad factors that explain disclosure and non-disclosure. Disclosure is more complex and necessarily nuanced than can be determined based on closed-ended survey questions. From a symbolic interactionist perspective, for instance, non-disclosure may be a form of concealment or protection from stigma while disclosure might be an integral aspect of a person's identity development. How individuals make decisions about one or the other is in many ways a response to social norms.

Previous studies tend to lack analyses of the effect of norms on individual decisions about conception disclosure. My research, however, recognizes the individual as a part of a social system and thus contributes sociologically by examining how individuals make decisions about conception disclosure given what is accepted or expected by society.

Numerous studies have examined the factors that motivate conception disclosure (Blyth et al. 2010; Hershberger et al. 2007; Readings et al. 2011; Shehab et al. 2008). Each study produced several reasons, but none that I know of has attempted to examine how these many factors correlate – if at all. In my analysis, I develop a scale to measure attitudes towards disclosure. This scale consolidates an extensive list of reasons for non/disclosure and established associations that stem from one or more underlying emotion. This scale contributes even more to our understanding of disclosure beyond simply identifying the different reasons.

My research also extends the application of two conceptual frameworks: medical consumerism and communication privacy management. Fertility treatment, as a specialized and often still inaccessible area of medicine, does not appear to be an area of medicine where patients exhibit consumerist behavior. This may be influenced by societal expectation that those who suffer with infertility are obligated to do everything possible to fulfill their motherhood mandate by becoming heavily dependent on biomedical technologies. My research contributes to the discourse here by adding a counter narrative to the patient as passive discourse and demonstrates that the fertility patient actively makes choices about where to obtain service, has expectations about the service, as well as makes demands and choices that reflect their personal desires. I find that fertility treatment patients as medical consumers do not simply choose between the two extremes of voicing their concerns and desire or terminating the doctor-patient relationship, they also collaborate with physicians to co-develop treatment plans. With respect to Communication

Privacy Management theory (CPM), my research shows additional application of the framework to broaden our understanding of conception disclosure. I use CPM as a launching pad to argue that there is a need in family communication theory to distinguish between information that is private and that which is sensitive, since disclosure decisions might vary on this basis. I also suggest ways in which the framework can be extended to capture a more sociological perspective on disclosure decisions.

The most significant contribution this study makes is the attention paid to sexual identity when it comes to fertility treatment and conception disclosure. Indeed, a lower access rate to ART is expected among sexual minority persons due to social, legal, and political barriers. Within the clinic setting, numerous challenges have also been identified, but for the most part the research is still sparse (Johnson 2012; Stern et al. 2002). Understanding how heterosexual experiences compare to sexual minority persons can further policy initiatives geared toward equal access and improved treatment of all persons. In the same vein, some of the same factors that structure access and shape treatment experience also influence conception disclosure behavior among sexual minority persons. My research therefore contributes to our understanding about the similarities and differences in conception disclosure based on sexual identity and the factors that shape those decisions.

VI. OVERVIEW OF DISSERTATION

The next two chapters of my dissertation continue to set the stage for this research project and provide an outline for the four substantive data chapters that follow. In Chapter 2, I provide a review of a vast body of research on parenthood desires, stratified reproduction, infertility, treatment experience, doctor-patient relationships, and conception disclosure. I draw on several theoretical frameworks also explained in Chapter 2: conflict theory, feminist theory, symbolic

interactionism, medical consumerism, and communication privacy management. I developed an original online survey to collect data for this dissertation project. In Chapter 3, I detail and justify the methodological approach taken in this process

Chapters 4 through 7 highlight the opinions and experiences of the women who participated in the survey. In Chapter 4, *The Fertility Patients' Experience Within the Medical Encounter*, I highlight participants' experiences of the treatment process and end with a comparative analysis based on sexual identity. In this chapter, I argue that even in a specialized field of fertility treatment, physician power is waning primarily due to two factors: medical uncertainty and the vast wealth of information available. The experience of reproductive medicine has been characterized by frequent and multiple attempts, misdiagnosis, and uncertainty about the outcomes. I also discuss the experience of fertility treatment as one that involves predetermined procedures and protocols, where treatment is unlikely customizable. Earlier models of medicine put forward by scholars such as Talcott Parsons (1975) describe patients as passive recipients of health care, who should conform to sick role, seek medical care, and submit to physician expertise. This model of the doctor-patient relationship, especially within a medical consumer model, is seemingly becoming less acceptable. My research demonstrates that fertility patients are not simply submissive recipients of treatment, but are instead strategic, agentic actors. These engaged fertility patients act as medical associates who take steps to influence their treatment through research, by challenging physicians, and discontinuing treatment when expectations are not met. Although sexual minority women had some unique experiences within the encounter, their accounts of the experience with respect to many of the more dominant themes that emerged did not vary.

The remaining chapters of the dissertation pay particular attention to conception disclosure. In Chapter 5, *Conception Disclosure Attitude and Behavior* I provide an analysis of the attitudes towards disclosure and further explore some aspects of disclosure decisions. Relative to the other chapters on disclosure, this one focuses on disclosure to family, friends, and acquaintances. Chapter 6, *Importance of Conception Disclosure to Children,* concentrates on decisions about divulging conception information to the child conceived with the technology. In Chapter 7, *Conception Disclosure Strategies,* I continue the focus on the child, but with emphasis on disclosure strategies. Disclosure is complex, often involving several actors and different pieces of information. Based on my data, I suggest that conception disclosure is motivated by care relating to the parent's desire to protect the child and demonstrate how much the child was wanted. On the other hand, non-disclosure is motivated by a fear of stigma, judgment, and identity loss. I argue, therefore, that the motivation to disclose is more centered on the private domain, to include interpersonal relationships, while non-disclosure is influenced more by public concern that is shaped by the socio-cultural context.

I further discuss the fact that parents manage conception information differently across groups of people. Based on my analysis of these patterns of conception disclosure I argue that heterosexually identified women are more engaged in selective disclosure compared sexual minority parents. Conception disclosure to children is important for several reasons and among them is the expectation that disclosure normalizes assisted reproduction. Although there is no set ART conception narrative, there appears to be some common features, including the notion of needing or receiving help from medical personnel and other altruistic persons. Additionally, some women romanticized assisted conception, which I interpret as part and parcel of the effort to destigmatize it. For these reasons, I argue that parents were engaged in what I call subversive

disclosure. Both heterosexually identified women and those who identified as lesbian, gay, or queer placed some importance on conception disclosure to children and when it comes to actual or planned disclosure parents employ either one or a combination of strategies.

CHAPTER 2

THEORETICAL FRAMEWORK & LITERATURE REVIEW

I. INTRODUCTION

In this chapter, I discuss the theoretical perspectives that frame my research and analysis. I draw on multiple frameworks: Conflict theory, Feminist theory, Medical Consumerism, Symbolic Interactionism, and Communication Privacy Management theory (CPM). I utilize both conflict and feminist theory, as well as, medical consumerism to gain insights about fertility treatment experiences explored in Chapter 4. In Chapters 5, 6, and 7, I use symbolic interactionism and communication privacy management theory to gain insights on parents' attitudes and behavior pertaining to conception disclosure.

This chapter further provides a review of the body of research that inspired my study. Given the nature of my research on the use of ART, I explore the literature on parenting desires and intentions. In addition, my interest in examining differences based on sexual identity necessitates a review of a more recent body of research concerning access to parenthood not just on the basis of sexuality, but other intersecting identities such as race and class. Medical Sociologists have been interested in understanding patients' experience within the medical encounter for years and have done significant work among infertility patients as well as those who suffer from other chronic diseases and illnesses. For this reason, I explore the literature on the experience of infertility and infertility treatment, as well as the more global literature that examines doctor-patient interactions. In my research, I place significant emphasis on conception disclosure. Therefore, it was necessary to explore the existing body of research on the topic. Overall, the body of work reviewed and discussed in this chapter establishes what is already known, missing from existing analysis, and not yet demonstrated by research.

II. THEORETICAL FRAMEWORK

CONFLICT PERSPECTIVE

Conflict theory draws attention to structural inequality, the relationship between those who hold positions of power and privilege and those impacted by them. In particular, I draw on a conflict framework to examine the ways in which social structure, which is composed of an interlocking set of social relations, privileges heterosexual two-parent families over single, gay, lesbian, and transgender parents (Connidis & McMullin 2002:558). According to Schwartz and Rutter (1998), "Traditional norms of marriage and sexuality have maintained social order by keeping people in familiar and 'appropriate' categories" while constructing unconventional family forms (i.e., single and same-sex parent) as deviant and disruptive to the social order (p.453). Legislation concerning marriage, and the myriad of rights and benefits which it inheres, is instrumental in delineating and protecting these familiar and appropriate categories of people and families.

To date, all 50 U.S. States have marriage equality after same-sex marriage was legally recognized by the Supreme Court in 2015. However, the law on adoption and legal parenting options for gay parents still varies across states. Patterson and Riskind (2010) opine that despite the leaps made to legitimize same-sex union and gains in accessing parenthood, existing barriers still dictate that many will remain childless. The lack of legal protection for same-sex couples and same-sex parents in most U.S. States begs for an examination of how lesbian women and transgender individuals, who are inhibited by social structural issues, gain access to parenthood through the use of reproductive technology and the precariousness of becoming parents. A conflict theoretical approach is, therefore, essential to critically exam how wider structural issues reach into, shape, and dictate individual choices about parenthood and how to achieve it.

Studies have found that some clinics restrict services to persons who are married and/or in heterosexual relationships. Scholars have found evidence of discrimination, heterosexism, isolation, and policing of sexuality in stories of lesbian motherhood, pregnancy, and birthing experience (Chapman et al. 2012; Peel 2009). Clinical environments and doctor-patient encounters are examples of areas where there are checks and balances directed at upholding the ideological concept of the traditional family. Thus, medicine, as a social institution, "serves as a gatekeeper determining who should and should not mother according to hegemonic norms of motherhood" (Bell 2010:632). Ultimately, single mothers, racial-minority mothers, and lesbian mothers become "subjects of deviancy discourses of mothering" (Arendell 2000:1195).

FEMINIST PERSPECTIVE

Some feminists have long been concerned with the ways in which medicine has taken up infertility with much vim and vigor. The medicalization of infertility, like childbirth, has continued to effectively convert women into "serviceable objects" and has done so for decades (Armstrong 2000:601). Mamo (2007) states that "infertility as a specialized knowledge, labels bodily states, behaviors, and desire in its own terms and places them under the regulation and control of experts for 'cure' and/or normalization" (p.158). For these reasons, some feminist scholars have vehemently critiqued the medicalization of infertility and the use of reproductive technologies, arguing that they function in effect to diminish women's control over their own reproductive bodies and reinforce women's roles as mothers. Strickler (1992) argues that the benefits of the medicalization of infertility and use of reproductive technologies are twofold to, "reinforce the necessity of childbearing for women's fulfillment on one hand, and physicians' increasing power in managing procreation on the other" (p.120). The spillover effect of this process of medicalization of infertility is that it reifies physicians' role as custodians of dominant

ideological norms – mainly that women should become mothers, although only some are deemed to be fit mothers (Bell 2010; Greil et al. 2011; Mamo 2007).

There are varying viewpoints within the feminist school of thought. Rushing and Onorato (2003) suggest that there are three feminist theoretical perspectives on the role of new reproductive technologies. The liberal perspective is that reproductive technologies are potentially liberating, but argue that ART must be structured in ways that safeguard individual rights to choose. The radical perspective is that new reproductive technologies are about patriarchal control over women and will only liberate women if they are the ones in control of the technologies. From a socialist standpoint, new reproductive technologies further alienate women from the reproductive process, maintaining that for it to liberate women there must be a "transformation of productive and procreative social relations" (Rushing & Onorato 2003:395).

MEDICAL CONSUMERISM

More recently, medical consumerism has gained increase interest among researchers. Frank (2000) provides historical context that dates the change from labeling individuals as patients to individuals as consumers to the 1970s and notes that medical consumerism was a language more popularly applied in the field of selective surgeries. From a medical standpoint, the patient-as-consumer idea holds patients accountable for their own health and self-care. This framework applies a market-oriented approach to healthcare, effectively making healthcare a commodity and views patients as rational decision makers, who through research, evaluation, and need, act within their best interest. Rodwin (1994) explains that medical consumerism is based on the understanding that "medical care is a service, like any other, and that patients are consumers who can choose who should provide medical services and even what kind of services to purchase" (p.153). He suggests that political movements have shaped changes in two

fundamental ways: first, by encouraging individuals to have a voice and to use that voice to share complaints and to promote their own interest; and second, to feel empowered to discontinue service in one place and seek medical care elsewhere (p.150). Seeking alternatives and filing complaints are therefore two responses to dissatisfaction in health care services. Hirschmann (1970) similarly refer to these two strategies as "exit" and "voice" (cited by Rosenthal & Schlesinger 2002:42).

The notion of consumerism in medicine has been examined by a number of scholars. One example is a study by Lupton (1997), where Australian participants suggested that physicians experienced status-loss over time, but were still respected. Participants were critical of physicians and were not reluctant to articulate whether they had received undesirable treatment. Familiarity with recent research, technical know-how, good diagnostic skills, and awareness of alternatives as well as empathy were among the qualities that participants associated with good doctors. According to Lupton (1997), "Patients *qua* consumers are urged to refuse to accept paternalism or 'medical dominance' on the part of the doctor, to 'shop around', to actively evaluate doctors' services and to go elsewhere should the 'commodity' be found unsatisfactory" (p.373). Participants, however, were well aware of the power imbalance within doctor-patient encounters that sometimes limited their ability to challenge them. Lupton suggest that there are minimally two barriers to the medical consumer approach: First, "asymmetry in knowledge," which is simply that patients are not equipped with the same specialized knowledge; and second, "dependency" due to patients' ill-health and desire to find a remedy (p.379). She further suggests that a consumerist approach encourages mistrust and therefore threatens to diminish the benefits of the doctor-patient encounter.

The medical consumerism framework can be critiqued in a few other ways. This theory, although useful in many ways for my research, does not fully acknowledge differences in access to information and services, which are often linked to socio-economic characteristics. If research inspires medical consumerism, the theory assumes that persons have, and act on, accurate health information obtained from available sources. Notwithstanding, I find the theory helpful in the exploration and analysis of the fertility treatment experience.

SYMBOLIC INTERACTIONISM

Symbolic Interactionism (SI) concerns the interpretative process through which meaning is made. Influenced by early SI thinkers, I am particularly drawn to William James' theorization of "selective interest," which he argues shapes consciousness and enables the individual to direct their attention to the aspects of experience that is necessary for a particular course of action (Inglis & Thorpe 2013:110). Also valuable is one of Herbert Blummer's central contributions, which is the idea of "self-indication," a process of recognition through which things enter individual consciousness and then serve as a mechanism to "construct, alter or revise potential course of action" (Inglis & Thorpe 2013:116). Most influential is the work of Erving Goffman's "impression management," which concerns how individuals consciously regulate their behaviors to put forward a positive self-image, especially in attempts to save face (Inglis & Thorpe 2013:122). In one of his most distinguished works, on stigma and the management of spoiled identity, Goffman (1963) discusses how labels and stereotypes get attached to individuals based on what is deemed normal and presents a number of strategies individuals employ to manage stigma, ranging from concealment to disclosure.

Symbolic interactionism is *sine qua non* to a sociology of infertility, reproduction, and biomedical reproductive technologies. SI is a useful framework to better understand identity

formation around infertility, medically assisted reproduction, and the management of this information in personal and public spheres. McQuillan et al. (2012) use identity theory, which has epistemological roots in symbolic interactionism, to discuss the importance of motherhood and how this has shaped behavior and experience in the American context. The authors argue that failure to fulfill this motherhood identity leads to "identity disruption." Moreover, they found that women who were childless due to biomedical reasons, and for whom motherhood was a salient identity, were more likely to have childlessness concerns. Miall (1986) discusses how women construct involuntary childlessness as "something negative," "failure," "an inability to work normally" (p.271). The women in Miall's study engaged in strategic information management, which Miall organizes into three broad categories: selective concealment; therapeutic disclosure; and preventive disclosure (p.274). Relatedly, Park (2002) discusses the stigma associated with individuals who are childless by choice, especially in pro-natalist societies, and who employ several techniques to control their personal information. With respect to infertility as a stigmatized identity and the use of reproductive technology, Lorber (2000) suggests that treatment seeking allows women to explore the possibility of having children, protected against social stigmatization with an opportunity for social recognition as an involuntarily childless woman (p.46).

COMMUNICATION PRIVACY MANAGEMENT THEORY (CPM)

Scholars in family studies have developed the Communication Privacy Management theory (CPM) to explain the process of disclosing confidential information. According to Galvin and Braithwaite (2014), the theory was developed "to explain how relational parties make decisions about revealing and concealing information" (p.100). Rauscher and Fine (2012) explain that CPM "uses boundaries as a metaphor to show how individuals manage private

information" (p.222). Citing examples from research about families created through ART, the authors find that individuals employ one of three privacy management processes. The first concerns a privacy rule foundation – this is where persons establish rules about disclosure pertaining to the when, who, where, and how. Circumstances will sometimes require that these privacy rules be reestablished or renegotiated, resulting in the second management process of boundary coordination operations, which has to do with the management of privacy information between self and others as well as the construction and maintenance of these boundaries. The third management strategy concerns boundary turbulence – attention to any rule violations that may occur and different perceptions about ownership rights and privacy boundaries.

Disclosure does not only and always mean full disclosure. Additionally, scholars have argued that privacy and disclosure are not opposites, but instead two extremes of a continuum. Petronio and Caughlin (2006) suggest that "privacy is a dialectic in nature…a simultaneous push and pull between both wanting to tell and wanting to keep something to ourselves" (p.36). Proponents of this theoretical framework argue that individuals are constantly engaged in the process of resolving the tension between privacy and disclosure. Petronio and Caughlin (2006) further suggest that private information can be personal or collective. Once shared to a collective, those individuals become shareholders and are therefore accountable for how they share it with other persons. In order to maintain privacy boundaries, individuals may develop rules to determine who the information will be shared with, the degree of co-ownership, and ways to regulate information sharing to a third party. The authors similarly discuss boundary turbulence as one aspect of CPM and describe it as occurring when there is a misunderstanding of the privacy rules or a disruption in the boundaries.

III. LITERATURE REVIEW

In this section, I highlight some scholarly work to provide context for my research. Individuals who pursue fertility treatment, it is believed, have high levels of parenting desires indicative of the time and resources they choose to invest in their efforts to conceive. However, research has shown that in spite of an individual's parenthood desires they might be denied access to such things as fertility treatment based on socio-economic characteristics, including sexual identity. Typically, medical personnel are the gatekeepers and so critical to my work on fertility treatment is understanding how patients experience treatment and the medical encounter. Infertility and treatment seeking experiences are among the many factors considered when parents make decisions about conception disclosure. The aforementioned matters are among the information discussed in this section.

PARENTING DESIRES, INTENTIONS & BEHAVIORS

Scholars have explored parenthood motivations based on fertility status. Langdridge et al. (2000) examined reasons for wanting a child among three groups of individuals: married expecting couples, couples with primary infertility problems about to receive IVF, and couples with male factor infertility problems pursuing DI. The authors found that reasons for having children were motivated by three main factors: the need to give love, receive love, and experience the enjoyment of children. Additionally, there was a strong desire to build a family in which essentially children have biological ties to both parents. Colpin et al. (1998) found that women who conceive naturally were similar in motherhood motivations to those who conceive by homologous IVF[3]. Among IVF mothers, however, identity, motherhood and social control

[3] Homologous IVF is done with sperms from the parents/couple (Colpin et al. 1998). On the other hand, heterologous IVF uses donor sperms (In Vitro Fertilization| IVF. Website: www.vitafertilidad.com/en/tratamiento/5/in-vitro-fertilization-ivf/ Retrieved February 6, 2017).

emerged as important factors that influence their desire for children. Dyer et al. (2008) found similar motivational factors among 50 South African couples with infertility challenges. In this particular study, happiness, parenthood, identity, well-being, and social control were all parenthood motivational factors found to significantly correlate with a strong wish to have children among the women in the sample. Baker (2004) did a qualitative study of couples in New Zealand who were undergoing fertility treatment and found women's narratives "perpetuated the cultural discourse that conflates femininity and motherhood and suggest that the normal family is a gendered one with two heterosexual parents" (p.31). Ulrich and Weatherall (2000) also qualitatively examined how women constructed their desire for motherhood in a way that was conflated with womanhood, where motherhood was seen as biologically destined and socially expected.

Research suggests that gay and lesbians have similar desires to have children as compared to heterosexuals, and "endorsed the value of parenthood" in similar ways (Riskind & Patterson 2010:78). Patterson and Riskind (2010) found similarity in the desire for motherhood between lesbians and heterosexual women, as well as evidence that lesbians might even place greater importance on parenting (p.330). While the literature is still developing in this area, in general, same-sex couples' desire, value, and enjoy parenthood in similar ways as heterosexual couples. Where differences have been identified, lesbian mothers tend to show an advantage in a number of areas. Bos (2003) found that lesbian parents had a significantly stronger desire for children relative to heterosexual parents. Biblarz and Savci (2010) also identified a number of studies that found strong desires for motherhood among lesbian women who gained access to parenthood though Donor Insemination (DI). Lesbian mothers were also found to be either equal or surpass heterosexual married couples in time spent with children, parenting skills,

demonstrating warmth and affection (Biblarz & Savci 2010:482). Based on a study involving women who achieved parenthood through DI, Bergman et al. (2010) reported that the women felt that becoming a parent was the best thing that ever happened and they found the process of watching kids develop and grow a gratifying experience (p.117).

STRATIFIED REPRODUCTION – RACE, CLASS, MARITAL STATUS & SEXUALITY

The paradox of infertility and treatment is that racial minority women are more likely to suffer with infertility, but are less likely to receive treatment (Bell 2009; Bell 2010; Greil et al. 2011). For instance, Bitler and Schmidt's (2006) quantitative analysis across multiple waves of the National Survey of Family Growth (NSFG) found differences in infertility status and access to treatment based on race, ethnicity, and SES. Findings from this study confirm that racial minority and less educated women are more likely to be infertile, but less likely to seek treatment. Furthermore, living in a U.S. State with mandated insurance provisions for infertility does not reduce these disparities. Jain's (2006) research, however, found that racial minority women were more likely to seek treatment only after a longer period of challenged conception, despite living in a state with mandated insurance coverage. Chambers et al. (2013) focused on socioeconomic disparities and found that women from higher SES quintiles were two times as likely to seek infertility treatment when compared to women from low SES quintiles.

Although U.S. national data have consistently found an overrepresentation of minority women with fertility issues but underrepresented in fertility treatment groups, studies that examine these differences have not been consistent in their findings and explanations. In a study of 391 prospective fertility treatment clients, Smith et al. (2011) found no effect of race, while household income and education were significant predictors of fertility service utilization as well as the type of services acquired. The authors asserted that social capital, greater knowledge, and

greater cultural acceptance of fertility treatment might account for increased access among high income and more educated women. Kessler et al. (2013) concluded that the use of fertility treatment is nonrandom based on an examination of associated factors, such as race/ethnicity, marital status, age, education, and income. They did not find an effect based on insurance.

Several suggestions have been put forward and examined in an attempt to explain this race differential fertility treatment access paradox. Greil et al. (2011) assert that the relationship between race/ethnicity and service access is mediated by income, education, and insurance, but not entirely. Stephen and Chandra (2000) found that treatment seekers were older, married, more educated, higher income white women with private health insurance. These findings suggest that race and ethnic differences were explained by education and income, leading the authors to assert a conflation of race and socioeconomic status as significant determinants of treatment access. Jain and Horstein (2005) found that African American and Hispanic/Latina women were underrepresented when it comes to infertility treatment in the state of Massachusetts irrespective of the mandated coverage of IVF. Services were predominantly accessed by Caucasians, highly educated, and the wealthy. The authors theorized that the "lack of appropriate information, racial discrimination, lack of referrals from primary care physicians, lack of adequate insurance coverage among lower socioeconomic groups, and cultural bias against infertility treatment" are potential explanatory factors (p.223). Other studies have found that the differences are explained away by insurance and socioeconomic status (Chandra & Stephen 2010). Steinburg (1997) found that the "single greatest factor accounting for the dominance of (White) middle-class patients in the IVF context is the direct cost of treatment cycles, together with the hidden costs of treatment" (p.40). The disparity appears, therefore, to be a complex interplay of factors including race, insurance, employment, cost, cultural beliefs, and politics. Bell (2009, 2010) connects the

disparity of treatment access to a culture of poverty mentality where black women from low SES backgrounds are blamed for their infertility resulting from their hypersexuality, and bouts of Sexually Transmitted Infections (STI). Middle and upper class women's infertility, on the other hand, is believed to be due to late marriage and the postponement of child birth for which they are empathized.

Studies that examine differential access based on sexuality are predominantly limited to meso-level analysis, in particular, clinic selection ethos, policy, and practice. According to a study of clinic selection criteria for IVF and GIFT treatment in Britain, Steinberg (1997) found that clinic selection was based on sexuality, lifestyle, financial status, as well as psychiatric and emotional st/ability (p.36). All but one of the 24 participating clinics refused treatment if the client was not married or in a long-term heterosexual relationship; intentionally excluding "ethically dubious" individuals, which characterized un-partnered and lesbian women (p.36). Stern et al. (2002) use the terminology "access-to-services issues" to describe "a dilemma caused by the presence of behaviors or conditions in the patient that the provider finds to be so problematic for ethical or other reasons that the provider is uncomfortable treating this individual" (p.537). A study of 184 clinic directors based in the U.S., found that among the biographical data used to justify the refusal of service is age, if persons are an unmarried heterosexual couple; if a woman is single; if persons are a lesbian couple; a woman is in poor mental health, has a history of alcohol consumption and marijuana smoking among several other factors (Stern et al. 2002:539). Overall, the two most common restrictions were imposed based on a perceived risk to patient or child (ibid., 540). Attitudes of the clinic directors reflected the policy of the clinic, but there were also cases where directors wanted to impose restrictions autonomously – beyond the written policy. Johnson (2012) found that approximately 90% of the

402 clinics included in the sample accepted single women, but less than a third (29.6%) recognized alternative family forms (based on an examination of their websites according to CDC and SART clinic data produced). The author also found exclusionary language on a number of websites that offered services specifically to heterosexual couples with infertility, DI for male factor infertility, and artificial insemination with husband's sperm. Gurmankin et al. (2005) used hypothetical situations to tease out the circumstances under which it was extremely likely that a prospective client would be refused treatment. Results indicate that 53% of doctors said they were very or extremely likely to refuse the client if he was a single male; 20% if a single female; 48% if gay couple wanted to use a surrogate; and 17% if lesbian couple wanted to use donor insemination (Gurmankin et al. 2005:65).

Overall, the findings pertaining to fertility treatment provision to groups of individuals, based on clinic samples, are mixed and appear to show some cultural specificity. One survey of clinics in Canada by Corbett et al. (2013) found that all except one of the 24 participating clinics offered services to lesbian women and all offered services to single heterosexual women. Only 17% of clinics had any written protocol, however, over 88% maintained non-discrimination on the basis of program policy. They also examined 32 clinics' websites and found that only 44% mentioned lesbian couples, and of those who mentioned donor insemination as a service offered, 27% had heteronormative cues directed at single heterosexual women or male factor infertility. The authors argue that subtle moral and ethical oppositions to providing care to lesbian women and their alienation through heteronormative intimations are among the main barriers to access (p.1080). In the case of Canada, not only is gay marriage legal, but the Canadian Assisted Human Reproduction Act stipulates that "persons who seek to undergo assisted reproduction procedures must not be discriminated against, including on the basis of their sexual orientation or

marital status" (Corbett et al. 2013:1079). Sperling and Simon (2010), based on a survey of 46 physicians in Israel, found that although guidelines were sometimes vague and seemingly lacking, between 95% and 100% said that they would provide services to unmarried couples, single lesbians, and gay males in stable relationships. The authors argue that what makes the case of Israel distinctly different from the U.S. is the pro-natalist policies of the country, which essentially discourages these forms of discriminatory practices. Rank (2010) broadly summarize that religious objections, moral and ethical determinations, limited financial resources, limited or complete lack of insurance coverage, discrimination, and legal issues are among the many barriers to ART use for gay couples.

THE EXPERIENCE OF INFERTILITY & TREATMENT

The failure to fulfill the motherhood mandate for many women becomes a source of stress, distress, depression, and anxiety, as well as creates communication and relationship problems (Greil et al. 2010; Schneider & Forthofer 2005). Women who place high value on motherhood as an identity and fail to realize that identity tend to suffer from "identity disruption" (McQuillan et al. 2012:1168). McQuillan et al. (2012) found evidence that childlessness concerns are highest for women with biomedical barriers to infertility, and these women were also more likely to report hearing messages that encourage child bearing and value motherhood. Cultural emphasis on the importance of motherhood indirectly but effectively denigrates childlessness and creates even more grief for women with infertility issues. Treatment becomes a significant stressor in addition to the experience of the infertility itself. Schneider and Forthofer (2005) found that stress was associated with the number of treatments, the duration, anticipated costs, and the relationship with the physician (187). On the other hand, some women feel empowered in the process of seeking medical assistance for their fertility (Parry 2006). Among

these women, seeking treatment is an act of agency, that demonstrates that they can and are doing something about their infertility.

The experience of ART among lesbian identified women has been documented by several researchers (Hayman et al. 2013; Peel 2009; Rondahl et al. 2009). Findings include telltale signs of the good, the bad, and the ugly within the market for assisted conception services. Wismont and Reame (1989) reviewed women's health literature and found that "lesbian pregnancy experience is characterized by the use of donor insemination, social discrimination and a dependence on peer rather than family networks for social support" (p.137). Lesbians must confront the issue of who will carry the pregnancy, which at times requires inventiveness and tactical maneuvers to be able to access reproductive technology (Renaud 2007). Research also suggests that lesbians often feel scrutinized, interrogated, and required to jump through hoops to "prove their worthiness as thoughtful recipients of DI who had considered the implications of their extraordinary family configuration" (Donovan & Wilson 2008:656). At times, clinic staff also attempt to normalize lesbian-headed families through questions about desire, capability to be good parents, and the availability of positive male role models. Participants in the study by Donovan and Wilson (2008), after coming to the recognition that the power structures were tilted in favor of clinicians as they could deny them a family, painted the picture-perfect family portrait for health practitioners.

Several studies have identified homophobia, heterosexism, and discrimination as characteristics of the lesbian women experience. Among a sample of 60 sexual minority women, mostly lesbian women who had suffered pregnancy loss, approximately 27% reported that they had encountered some form of heterosexism during the treatment process (Peel 2009). In a qualitative study involving 15 lesbian couples in Australia, Hayman et al. (2013) found several

accounts of systematic and institutional homophobia in various forms to include exclusion, heterosexual assumptions embedded in forms and other documents, inappropriate questioning, and flat out refusal of services (p.121). Societal norms concerning the standard family structure are reinforced in subtle, but effective ways through the language of intake forms, classifications of next-of-kin, posters and pamphlets in prenatal waiting rooms, clinics, pediatric offices and hospitals. One participant in a study by Rondahl et al. (2009) describes an experience where in a mixed couple setting, a health practitioner uniformly used heteronormative labels and dyads – such as "the father can sit here," "the woman and man," "the man," and "the father" (p.2341). Similar to findings from other studies, participants described situations in which the non-biological mother was not recognized and sometimes referred to using familial labels, such as mother or sister.

The erasure of queer, non-normative, non-traditional family forms from certain institutional spaces does not appear to be fortuitous, but rather motivated by a value-laden intentionality. Discourse, both written and spoken, works in multiple ways to legitimatize some family forms over others, for instance, when standard health forms and websites recognize only opposite-gender parent unions. For example, in the Corbett et al. (2013) study of fertility clinics and their websites previously cited, 27% provided "heteronormative descriptions," by repeatedly referring to the woman's male partner with respect to sperm donation or as the source of the problem for infertile couples (p.1079). These are the mechanisms of control within the medical setting - the emphasis on heteronormative ideals about reproduction and parenthood, which "privileges heterosexuality as the standard" and only viable option for reproduction and parenting (Johnson 2012:395). Lesbian mothers are almost always, therefore, negotiating this production and performance of heteronormativity (Malmquist & Nelson 2014:58).

Research on the experience of lesbian mothers during the medical encounter has produced mixed findings as well as varying understandings and articulation of their experiences. In a Swedish study of 96 lesbian parents, Malmquist and Nelson (2014), for example, construct two forms of repertoires based on interviews. Participants complained about constant heteronormative cues, such as signs that read mother and father, together with the exclusion of the non-birth mother, which the authors interpreted as a heteronormative repertoire. On the other hand, participants used a "just great" repertoire to describe these experiences as exceptions rather than the rule; overshadowing them with other positive experiences (Malmquist & Nelson 2014:61). The authors assert that the "just great" repertoire was potentially a way of refraining from vulnerability and compensating or contradicting existing negative notions about lesbian parenting. Similarly, Lee et al. (2011) found that lesbian mothers interpreted negative experiences during the medical encounter as a personality issue or having to do with the organizational culture of the hospital. These forms of rationalization are thought to be a protective mechanism mainly to preserve dignity and personal identity (Lee et al. 2011:987).

PATIENT-CENTERED INFERTILITY CARE & TREATMENT DISCONTINUATION

Studies, particularly in the medical field, have given much attention to patient-centered infertility care and the factors that lead to service dis/continuity. Van Empel et al. (2011) found that patients preferred clinics closer to home, but were willing to trade proximity for a clinic that is patient-centered. Based on their study involving 925 patients and 227 physicians, the authors found that patient-centeredness was a priority for patients, while successful pregnancy rates were a priority for physicians. Among 838 of the patients, 55% changed clinics for nonmedical reasons to include lack of patient-centeredness and lack of success or disagreement with treatment policy (p.589). The authors suggested the reason for this is that, "evidence-based medicine is disease-oriented doctor-centered, as it focuses on doctors' interpretation of scientific

research rather than on patients' individual needs and preferences" (p.589). In an editorial piece, Gleicher and Barad (2010) present counterarguments to the idea of patient-friendly IVF care. The authors claim that "In vitro fertilization has developed into a clinically mature procedure with expected pregnancy rates, entitling patients to achieve pregnancies at those rates" (p.2). They further explained that any modifications to the IVF process has the potential to compromise the results and thus, strongly advised against deviating from already established processes until it is proven that the gains compensate for any loss in pregnancy success rates.

A number of studies have alluded to a correlation between features of patient-focused care and client satisfaction with fertility treatment. Leite et al. (2005) found that overall women were satisfied with physician's communication skills during infertility consultation. Four factors that emerged as the strongest predictors of satisfaction were: physician introducing him/herself, outline of the reason for the visit, providing information about treatment, and showing regards for patients concerns or issues (p.42). This led the authors to conclude that "part of patient satisfaction derives from a dynamic interactional process with medical professional" (p.44). In a study of over 200 Finnish women who sought medical assistance to conceive, Malin et al. (2001) found that 45% reported being satisfied with their fertility treatment because they were given information that clarified their infertility issues and had positive experiences with doctors and nurses including supportive, empathic, friendly, and communicative encounters. Unsuccessful pregnancies, perception of inadequate care, poor doctor-patient relationships, as well as variation in the doctors seen, were among the common reasons of dissatisfaction. One U.S. based study by Groh and Wagner (2005) found that women were generally satisfied with the communication and delivery of the results of their ART cycle and reported feeling emotionally supported by healthcare professionals. However, women, who were alone when they received the results and

those who had negative results were more likely to express disappointment in the communication approach.

A number of factors explain clinic discontinuation. Based on meta-analysis, Gameiro et al. (2012) identified 24 such reasons for fertility treatment discontinuation, which are broadly classified under psychological, physical burden, and financial issues. Among them were clinic related issues; alternative options and abandonment; and doctors censoring. The authors found minor differences based on the stage of treatment, as well as significant overlaps at some stages. Additionally, they found that studies were focused on patient predictors, such as infertility history, duration, and treatment, but showed less concern about issues pertaining to clinic predictors of discontinuation or even factors important to patients. The authors also pointed out that studies are usually based on medical perspectives and tend to provide structured response options when asking about discontinuation. Boivin et al. (2012) reviewed the literature and found that authors identified fear and negative treatment attitudes; psychological and emotional factors; and relational strain as patient-related factors explaining discontinuation. Within the clinic domain, sub-optimal organizational care, which constituted lack of information sharing, inconsistencies, depersonalization, lack of continuity, negative doctor attitudes, and overall poor patient-staff interaction were factors that lead to discontinuation.

CONCEPTION DISCLOSURE

Several common reasons for conception disclosure have emerged in the literature: the right of the child to know; trustworthiness within the parent-child relationship; protecting the child from accidental disclosure; as well as personal testimonials from other individuals (Blyth et al. 2010; Hershberger et al. 2007; Readings et al. 2011; Shehab et al. 2008). Hershberger et al. (2007) summarized these factors among others within two broad themes: “values and beliefs”

and “social and cultural influences.” In their study, individuals discussed a right to know ideal that included the child, family members, and healthcare professionals. Social and cultural factors took into consideration a family culture of openness as well as perceived social support. Women are more likely to disclose if they get the sense that they were accepted and supported, whereas a sense of judgment and rejection impeded disclosure.

Disclosure is sometimes justified as a “labor of love” premised on the idea that if the child knows their conception story, they know how much they were wanted (Mac Dougall et al. 2007:528). Studies have consistently demonstrated, however, that deciding why, when, what, and how to divulge conception information is difficult for many. Explanations offered for non-disclosure include that it is unnecessary; it is personal and disclosure gives it unwarranted importance. Other explanations include fear that disclosure will lead to identity disruption, cause the child to feel abnormal, and potentially have deleterious effects on parent-child and extended family relationships (Applegarth & Riddle 2007; Lycett et al. 2005; MacCallum & Golombok 2007). It appears, then, that in many circumstances non-disclosure becomes a defense mechanism; a way of preventing unnecessary exposure to harm. Studies have found that non-disclosure can be a delay strategy, often justified on the basis that the child was too young, waiting for the child to ask, and an admission on the part of the parents that they are lacking the know-how (Landau & Weissenbury 2010; Readings et al. 2011). McGee et al. (2001) argue that the unintended adverse consequences of non-disclosure and the child’s need to know their medical history and origin outweighs parents desire for privacy and the perceived associated benefits. They claim that advances in genetic testing makes secrecy more unsustainable.

Counseling and assistance with how to approach the subject, as well as timing and specific language, are critical to the process of disclosure. Studies have demonstrated that

individuals would be more willing to disclose if they had access to appropriate, child-friendly literature (Peters et al. 2005). Research shows that individuals often get no information or conflicting information from clinic staff, mental health personnel, and physicians about whether to tell their offspring their conception story. Blyth et al. (2010) found within their sample that seven participants did not receive professional advice, six were told to tell their children, and five were advised not to.

Disclosure is a "complex multifactorial, and dynamic process" often compounded by other related aspects of the conception story (Hershberger et al. 2007:294). Some of those factors include parents' own struggle with infertility; the presence of other siblings; genetic origins; relationship with donor; family resemblance; thoughts about what the child might do with the information; as well as the type of medical assistance used to conceive. For example, Readings et al. (2011) compared donor insemination parents, egg donor, and surrogate parents and found that by the time the child was 7, disclosure was lowest among DI families and highest among surrogacy families, especially among those genetically related to the child. DI parents also had the lowest intentions to disclose. DI mothers more frequently expressed a desire to be honest, while Egg Donor (ED) mothers were more likely to say that the child had a right to know and surrogate mothers were motivated to avoid accidental disclosures. Mac Dougall et al. (2007) found that DI couples were slightly more likely to have already disclosed while a slightly higher proportion of egg donation couples had not yet disclosed, but planned to. Taken together though, egg donor couples were more likely to disclose or express intention to disclose when compared to DI couples. Peters et al. (2005) also found a significant effect based on method of conception (IVF or ICSI) and also a positive correlation between disclosure to offspring and informing other adults. Rosholm et al. (2010) found that not using donor gametes was a significant predictor of

disclosure; in other words, those who used donor gametes were less likely to disclose. They also found that parents were more likely to disclose to children if they had already disclosed to acquaintances. MacCallum and Keeley (2012) found that women who had conceived with donated embryos were less motivated to share conception information when compared to IVF and adoptive mothers. The authors suggest that for embryo donation mothers the reluctance to share is influenced mainly because of a third-party involvement.

Studies have also found evidence of a correlation between stigma and disclosure. Slade et al. (2007) found a negative relationship between perceived stigma and disclosure among men. Although the relationship was not statistically significant for women, they reported higher levels of stigma, which more positively influenced their disclosure behavior. Jansen and Onge (2015) also found evidence of perceived stigma among women who experienced fertility issues. They found that women in an online forum made attempts in their discussions to challenge what the authors refer to as "stigma power"[4] through attempts to stigmatize fertile women (Jansen & Onge 2015:186). Greil (2002) similarly found that women internalized their infertility as a stigmatized identity even though it is not visible. The author found that the women's experiences were more consistent with a felt stigma and further stated that, "Infertility is, then, a 'secret stigma,' hidden from outsiders, but nonetheless deeply felt (Greil 1991a, 1991b).[5] That this is the case says much about the power of social expectations about the "normal" life course for women…" (Greil 2002:106-107).

[4] Jansen and Onge (2015) adopt a conceptual definition of stigma power as "uni-directional, where the 'normals' have access to the power and avenues for exclusionary and discriminatory behavior to prevent status gains (keeping people down), to maintain social norms (keeping people in), or to present social barriers (keeping people away) (p.185)."

[5] Scrambler (1984) distinguishes between *enacted stigma*, which concerns discernible discrimination from *felt stigma*, which concerns internalization of a feeling of failure that they do not meet "standards of normality" based on societies expectation (cited by Greil 2002:106).

When it comes to disclosure strategies, Mac Dougall et al. (2007) identified two: "seed-planting" and "right time" (p.526). Seed-planting refers to telling children from an early age so that they always have knowledge and understanding of their conception story, which arguably makes disclosure less of an event or one-time thing. These responses are similar to those provided by participants in study conducted by Blyth et al. (2010), especially with respect to making disclosure uneventful and normal through early discussions and throughout the child's life. According to Mac Dougall et al. (2007), the "right-time strategy" is where parents take advantage of any "window of opportunity" that presents itself, while the seed-planting strategy is more a one-time event and when the child is both mature and cognitively developed to be able to understand and handle the issue (p.527). For some, disclosure was less of a decision and more "an evolution of the social process" (Hersberger et al. 2007:293). Likewise, Readings et al. (2011) found that the conception story unfolded in layers. There was evidence of partial disclosure to children about surrogacy or IVF with some intentional omission of slivers of the child's biography concerning donor eggs. With respect to disclosure to other persons, parents engaged in selective disclosure, always making decisions about who and how much they shared.

Many studies discussed ART disclosure as akin to adoption disclosure. Indeed, many of the anxieties identified by parents concerning the effect of disclosure or non-disclosure are shared across different groups – those who use ART (with or without donor gametes) and adoptive children. Wydra et al. (2012) suggest that concealment was commonly recommended prior to the 1970's. Since then, however, psychologists and family therapists have come out against a practice of secrecy and a number of studies highlight open communication as beneficial to children's development. Earlier clinical studies found evidence that early adoption disclosure adversely effected the child's developmental process, mental and emotional stability, as well as

cognitive functioning (Wieder 1977). What appears to be significant, though, is the timing as well as the way the story unfolds as these fundamentally shape the way children understand and internalize their conception.

Studies have also explored the experience of disclosure from the perspective of adoptees themselves. Of the 18 participants in a study by Wydra et al. (2012), several stated that they already knew and were satisfied overall with how disclosure took place. A smaller group of three persons expressed disappointment in the fact that their parents chose to withhold the information and were also displeased with how they learned about their adoption. Interestingly, although there was an overall practice of open communication, dialogue about the adoption was kept to a minimum because the children felt the need to protect their parents from the stress of disclosure.

Other studies have focused on disclosure from the perspective of parents. One study in India found that adoption disclosure was influenced by the child's age, parents' experience of infertility, and overall attitudes toward disclosure (Mohanty et al. 2014). The study also found that non-disclosure was supported by claims that it was unnecessary to do, issues with identity development, effect on mental health, and overall concern about the wellbeing of the child. Disclosure on the other hand, was a desire on the part of the parents to maintain an open and honest relationship with their children and to minimize exposure to accidental disclosure. Parents who rejected disclosure refuted the existence of difference between their own family and those considered biological, and those who supported disclosure more consistently acknowledged such differences. Another study examined disclosure among African Americans and found similar justifications about trust and protecting the child from accidentally being informed (Alexander et al. 2004). Attempts were made to ensure that disclosure stories were told positively, which sometimes included expressions of love, being "special," and being the "chosen child" (p.454).

Parents carefully considered the timing of disclosure based on the child's stage of cognitive development. Some parents appeared comfortable with disclosure while others were fearful of the consequences specifically in terms of their parent-child bond. Starting the conversation early and letting the story unfold allowed the information to congeal and in the longer run had more positive outcomes. When disclosure occurred, it was done with "sensitivity and imagination" (p.453).

IV. SUMMARY

There is limited sociological research pertaining to the experience of pregnancy and childbirth, especially among persons who conceive with medical assistance. I draw heavily on a body of work conducted by physicians and nurse researchers who are interested and involved in obstetrics and gynecological care as well as psychology and social work. Altogether, studies have to some extent explored: treatment selection; the experience of pregnancy loss; client satisfaction and the doctor-patient interaction within the clinic setting; and transition to parenthood among infertile couples, at times comparing them to others who achieved pregnancy naturally (Chapman et al. 2012; Gartrell et al. 1999; Łepecka-Klusek & Jakiel 2009). Still, sociological studies that examine topics pertaining to the experience of fertility treatment have not paid particular attention to sexuality.

Previous studies illustrate that disclosure and disclosure strategies are complicated by issues of infertility, genetic ties, stigma, and identity disruption. What is striking about the existing literature on the experience of fertility treatment and conception disclosure is that they come from the perspective of a wide cross section of researchers from different intellectual traditions. From a sociological perspective, however, a structural analysis of power dynamics within the medical encounter for fertility treatment is lacking. The process of disclosure for an

individual whose sexual identity is incongruent with dominant social norms concerning pregnancy and parenting is still a largely understudied area. This dissertation broadens our understanding of the multi-dimensionality of disclosure decisions across not only a diverse population, but also varied forms of assisted conception technologies.

Reproductive technologies allow people to construct the families they choose and establish familial relationships they prefer. Sociology of reproduction and the family calls for a better understanding of different family forms especially those created with the use of reproductive technologies. This research adds to a growing body of literature by exploring the significant shifts from *sex=reproduction* within heterosexual marriage *[Heterosexual marriage (sex=reproduction)]* breaking apart this equation to recognize sex as separate from reproduction and reproduction as separate from heterosexuality and marriage *[(sexuality)(marriage)(sex)(ART) = reproduction]*. Given advancements in medical technology, attempts to expand definitions of infertility and ART, the increasing visibility of gay, lesbian, and transgender individuals' desire for parenthood, and the booming baby market economy, the moment is ripe for sociological research in this area.

CHAPTER 3
METHODOLOGY AND RESEARCH DESIGN

I. INTRODUCTION

In this chapter, I provide an overview of the research design that I planned and executed during this project. I focus the discussion on some of the most critical considerations and justifications for utilizing an online survey for data collection. I further discuss the analytic techniques utilized to examine the stated research questions, both of which are the basis for the analyses presented in subsequent data chapters. I use qualitative and quantitative analytical strategies across chapters based on the nature of the research and survey questions. In summary, Chapters 4, 6, and 7 present an analysis of qualitative responses. Chapter 5, on the other hand, is a quantitative chapter and so an overview of the statistical techniques is discussed, separately, later.

II. RESEARCH DESIGN

This dissertation project uses primary data based on a cross-sectional research design. I designed a web-based survey to gather data guided by the main objective of examining differences regarding the experience of the medical encounter and conception disclosure attitudes, behavior, and experience among ART users based on sexual identity. Within the last decade and a half, there has been an explosion of qualitative and quantitative research in this area with emphasis on specific populations. However, knowledge and understanding about decisions, experience, and discourse around medically assisted conception based on sexual identity is still in an embryonic stage. This project, therefore, follows an exploratory design intended to provide useful insights, especially in this area where very little is known. Although research on assisted conception is not entirely new, a non-clinical study focused on experience and information sharing is for the most part uncharted territory.

For the purposes of data collection, I administered a web-based questionnaire. According to the 2013 American Community Survey (ACS), approximately 84% of households have a computer, 74% report internet use, and 73% report having high speed connection (File & Ryan 2014). The prevalence of internet use is highest among those employed; educated (some college and above); whites and Asians; younger populations mostly below the age of 44 years; and those in metropolitan areas. The increase in computer access, as well as the growth and development of the internet, has led to an upsurge in the use of internet based surveys. In a study by Lagan, Sinclair, and Kernohan (2010), women admitted to using the internet to search for pregnancy-related information and products (p.110). The study participants also suggested that the internet was a helpful source of information that either aided decision making or served to further elucidate certain issues. In a study by Epstein et al. (2002), participants categorized as "outleters" used the internet as an outlet, which gave them validation, support, and a place to have dialogue while those considered "alternate outleters" admitted to using the internet to share signs, symptoms, news, and for support (p.513). Weissman et al. (2000) also did a study to examine internet use among persons undergoing ART treatment and found that a little over half of the participants had used the internet for fertility-related topics, four out of every five searched for medical information on infertility diagnosis and therapy, another one half evaluated clinics, and a quarter sought self-help groups (p.1181). These and similar findings have helped to establish the internet as a go-to resource on reproduction and other related matters.

Online surveys offer several advantages over other data collection methods. Internet based surveys are less expensive; can be disseminated quickly; facilitate immediate returns; provide easy export to statistical software; have fewer response errors; circumvent the possibility of data entry error; and have a significant geographic reach (Hunter 2010). Internet-based surveys also allow

for the inclusion of graphics and other aesthetic decisions that can effectively boost participation and enhance participants experience. For example, Qualtrics, the software used to develop and host my online survey, provides additional features, which include allowing participants to view the survey in a cell phone mode, convenient for persons who access the survey using a mobile device. For participants, online surveys are convenient and allow the autonomy to decide when and where to take the survey, which is particularly comforting for people who suffer from social anxiety (Ward et al. 2012). Wharton et al. (2003) also mention that online surveys provide "social distance" between the researcher and participant, which might allow for more honest responses (p.1458).

In addition to the advantages of online surveys already discussed, I created the survey to be distributed via the web for the following specific reasons. First, reproduction in general, and the use of assisted fertility technique in particular, is more or less a private matter. Participants may therefore be more inclined to participate if they are in their own private spaces and not face-to-face with a stranger. Read et al. (2009), for example, found that web-based surveys provided unobtrusive and reliable results in measuring sensitive information among college students (p.100). Secondly, the target population is geographically spread across the United States. Finally, there is an already existing online presence in the form of support groups, discussion forums, blogs and YouTube videos that document infertility diagnosis, experience, and treatment. For these reasons, I identified an online survey as the most viable option for the purposes of this research. As stated, web-based surveys are ideal especially in circumstances where the target population is geographically dispersed or not easily identifiable, as well for subject matter that is considered confidential.

Despite the many advantages, there are also some identifiable pitfalls with online surveys. These include that it may yield lower response rates; the sample is usually non-random and unrepresentative; it requires technical skills and resources to get set up; it is completed in an uncontrolled environment; there can be issues of accessibility; and it can elicit shorter responses (Hunter 2010; Ward et al. 2012). There are also challenges with disseminating information about the online survey to potential participants. For example, spam mail is a potential issue since legitimate communication is sometimes indiscernible from junk mail. Additionally, unsolicited or unexpected email that invites survey participants might be considered intrusive or offensive (Wharton et al. 2003:1458). Also, online surveys usually require that participants have some basic computer knowledge. The level of skills required to complete a computer based survey dictates whether one will participate or not, the ease with which the participant navigates through the survey, as well as the quality of the response.

Data security is a huge concern when it comes to online surveys and survey data storage in general. Publicized accounts of email passwords and other online storage accounts being hacked amply demonstrate that the internet is not the safest place to store private and confidential information. As a consequence, my research participants were cautioned about the risk of sharing sensitive information across the internet. Although Qualtrics, the software I used to develop and that hosts the survey, maintains a secure data storage platform, Syracuse University IRB maintains that respondents should be reminded of the possible risks. I have also removed personal identifiers, IP addresses, and location information recorded by the software from all downloaded data, which is being stored on a password protected computer. Although these precautionary measures are in place, data security threatens the viability of online surveys.

SURVEY INSTRUMENT

The survey was administered electronically using an online web software, Qualtrics, under a license agreement by Syracuse University. This online program facilitates the design, development, dissemination, and monitoring of surveys. The software allows limited data analysis and summary statistics that can be customized by the researcher. It also facilitates further statistical analysis by making the data downloadable in other formats such as Excel and SPSS. Another advantage with the software is that it generates a Quick Response (QR) Code, which allows for direct access to the survey using a QR Code reader available for download on most mobile devices.

I developed a 74-question internet survey instrument, which included a combination of scales, open-ended questions, close-ended questions, as well as comment boxes to invite and encourage participants to share their experience of ART and decisions about disclosure (Appendix A). The questionnaire had six sections: Socio-demographic & Background Information; Motivation & Intention to have Children; Medical Assistance & Conception; Pregnancy & Birth Outcome; and Childbirth, Medical Encounter & Disclosure; and Closing Out – Demographics. Section one included 10 close-ended, socio-demographic questions such as age; race/ethnicity; relationship status; U.S. state of residence; education; employment; sexual and gender identity. Section two included one question on parenthood desires with 18 items measured on a four-point scale from very important to not important. The second question in the section measured future desire for children. Section three included 19 questions including: age first sought medical assistance; type of assistance sought; the use of donor embryo or sperms during successful treatment; infertility experience; duration, number and coverage of treatment; and support system. Section four had a total of six questions on lifetime pregnancies, pregnancy

loss; and the number of pregnancies that resulted from ART. Section five included 30 questions which asked for information about the decision to use a clinic and the experience at the clinic; refusal of service, treatment discontinuation with doctor or clinic and; experience of fertility treatment, pregnancy and giving birth. The section also included a number of questions on conception disclosure to physician and other professionals, acquaintances, friends, family and children. Respondents, who had disclosed, were asked to describe how they had done it. Another 18 items, measured on a five-point Likert scale from strongly agree to strongly disagree, inquired about the respondent's overall attitude towards disclosure. The final section included seven questions about partner's sex and gender identity; income; and religion. The last question, an open-ended question, asked respondents to add any further information about their experience that they would like to share.

Although clear instructions were provided on the eligibility requirement, the survey also included screening questions to determine if the respondent met the criteria for the study. Based on the three main criteria for taking the survey, participants were asked their age and U.S. State of residence. The main screening question was strategically placed among the questions about pregnancy history and asked, "*How many of those pregnancies resulted from the use of medical assistance?"* If the answer was equal to "0,"' then the participants were thanked for their participation and immediately filtered out of the survey.

To improve the validity of the questions and instrument I referred to a number of existing national and institutionally funded surveys and survey reports. Survey questions on infertility and reproductive history were inspired by the National Survey of Family Growth (NSFG)[6] and

[6] 2006-2010 NSFG: Public Use Data Files, Codebooks, and Documentation. Website: http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0107104

National Survey on Fertility Barriers (NSFB).[7] Questions on pregnancy and birth were informed by the Parental Age and Transition to Parenthood Australia (PATPA) study based on a select set of questions obtained from Cathy McMahon, a member of the research team. Questions regarding sexual and gender identity were influenced by a joint research report from the Fenway Institute and the Center for American Progress.[8] Survey questions were also inspired by clinic-based research conducted by Lass and Brinsden (2001) and I also adopted and modified a parent-motivation scale utilized by Dyer et al. (2008) (originally developed by van Balen & Trimbos-Kemper 1995) as part of the survey.

PRETEST

The questionnaire was pretested using an expert review model, which prioritizes research participants as experts of their own experience. The pretest took place over the period February 11-22, 2015. A total of five women, who used ART, were asked to take part in the pretest exercise. Respondents were asked to carefully record their responses, misunderstandings, and questions regarding the instrument. They were also encouraged to include comments about their reaction to the questions and any challenges they had understanding or identifying appropriate responses. In an effort to ensure the validity and reliability of the instrument, the pretest checked whether questions were easily understood, if they measured what was intended, if response options were mutually exclusive and exhaustive, if skip patterns functioned correctly or were needed, and if respondents interpreted the questions in the same way. Additionally, the pretest helped determine if the instructions for completing the questionnaire were clear and whether the estimated length of

[7] National Survey of Fertility Barriers (NSFB). Website: http://sodapop.pop.psu.edu/nsfb_page1.html
[8] Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, et al. (2014) "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers." http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0107104

time taken to complete the questionnaire was accurate. Pretest participants were provided with the following list of things to consider as they completed the survey:

1. *Questions* – Do you understand the questions? Are the questions clearly stated? Do any of the questions make you uncomfortable?
2. *Response options* – Are the response options that you want available?
3. *Design of the instrument* – Is the survey easy to navigate? Do the questions flow well? Feel free to make other comments about the look and feel of survey.
4. *Length of the survey* – How long did it take you to complete the survey? Is it too short, about right, or too long?

The five participants provided substantial feedback that improved the survey through their suggestions to include additional response options and questions. They also identified areas where clarification was needed. At least one participant expressed concerns that the survey did not allow them to share details about their experience and as such an optional open comment box was included to allow participant to share more details if they so desired. Changes were incorporated based on the pretest before launching the survey on March 9, 2015 (see Appendix B for pretest feedback).

III. DATA COLLECTION

The survey was available online from March 9, 2015 to January 15, 2016. I shared the call for participants across an estimated 500 emails and listservs; posted it on websites and online forums; and advertised by flyer. To increase participation of sexual minority women and transgender participants, I purposefully targeted fertility clinics and listservs that cater to Lesbian, Gay, Bisexual, and Transgender (LGBT) populations and support groups. I received support from a number of individuals, stakeholders, and major organizations to publicize the

survey such as Pride and Joy Families: Lesbian and Gay Family Building Project, the Family Section of the American Sociological Association (ASA) and RESOLVE: The National Fertility Association. RESOLVE had specific application procedures for the call for participants to be hosted on their website; they required completion of an application form, draft of the instrument, among other supporting documents. The survey was also hosted on MassEquality.org and posted on IVF-Infertility.com in a forum on "Pregnancy after Treatment." Flyers were also posted on the notice board or were accessible in several educational and medical institutions, including a fertility clinic located in Syracuse, New York (Appendix C). These flyers were designed with QR Codes, which are readable using anyone of several apps designed for IPhone and Androids, to conveniently access and complete the survey using a cell phone device.

PROTECTION OF HUMAN SUBJECTS

This project was approved by the Syracuse University Office of Research and Integrity Protections (IRB reference #14-344) on December 22, 2014 (Appendix D). A modification was made to allow for the inclusion of a flyer as an additional recruitment material. Approval for this modification was granted on December 7, 2015 (Appendix D). The survey cover letter informed participants about the purpose of the study, eligibility requirement, as well as issues pertaining to privacy, confidentiality, and anonymity. Persons were also provided with instructional information about the survey, the estimated length of time for completion as well as contact information for my adviser, Janet Wilmoth and myself. Persons were further advised that informed consent was implied once the participant proceeded with taking the survey. The cover page detailed that participation was voluntary and that participants could refuse to answer a question or exit the survey at any time without penalty. Participants were provided with support resources due to the potentially sensitive nature of the survey questions, which ask participants to describe their

experience with infertility, desire to have children, spousal and family support as well as birth and medical history. This presented the best alternative given my inability to determine the risk of harm, especially emotional harm that questions could invoke. Although persons were not asked to include identifiable information on the survey itself, some information obtained through the software that would aid in geolocating the survey participants were removed to protect participants' identity.

SAMPLING

This dissertation research is based on a purposive sampling technique that targets a specific population of persons who had used ART to conceive, intentionally selected based on their expert knowledge of the subject matter. A purposive sample is useful when the objective is to obtain cases, using different methods, which fit the specific criteria consistent with the research objective (Newman 2002; Wysocki 2003). The unit of analysis was individuals 18 years and older, living in the United States, who have successfully given birth to at least one child conceived with the use of assisted medical technologies. Since there is no publicly available data base for individuals who have successfully conceived with medical assistance, selecting a representative sample is impossible. I further relied on snowball sampling by asking individuals to forward the call for participants to other entities and individuals in their network to assist with getting additional survey participants.

IV. SAMPLE CHARACTERISTICS

DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Over the 11-month data collection period, a total of 186 persons visited the survey, 125 of whom submitted their survey responses. The overall survey response rate was 67%. It should be noted, however, that surveys that are incomplete at the time the survey expires are

automatically closed and the data included. For the purposes of the analysis, respondents were dropped from the sample if they did not meet the basic criteria for the survey; which is that they gave birth to at least one child conceived with medical assistance. Therefore, persons were dropped from the analysis if they responded "0" or were missing on a follow-up question concerning their pregnancy history that asked how many of their pregnancies were as a result of medical assistance. After an examination of response consistency, two respondents who indicated that they were assigned male at birth and male identified were excluded from the sample. In the end, the analytical sample is 114 women.

Participants were on average 39 years of age, with ages ranging between 23 and 67 years. As shown in table 3.1, the sample was overwhelmingly white (91%) and non-Hispanic identified (94%). Almost nine of every 10 women (86%) were married at the time of the survey. Participants lived in 34 states across the United States at the time of the survey. Approximately 30% of the sample resided in the Northeast region of the US; with the state of New York having the single largest representation at approximately 17% of the entire sample. Another 28% resided in the South region of the U.S. The sample is mostly college educated with about 27% having earned a bachelor's degree, 30% a master's degree and 32% a doctorate. Seventy-four percent were employed full-time and another 15% had part-time employment. With respect to sexual orientation, 78% identified as heterosexual, 14% as lesbian or gay and 6% as bisexual. A little under one half of the sample had no religious preference (43%), 21% were Catholic, and 12% were Protestant.

TABLE 3.1: DEMOGRAPHIC CHARACTERISTICS OF SURVEY PARTICIPANTS

Variables		%	N
Sexual Identity			
	Heterosexual	78.1	89
	Lesbian	13.2	15
	Gay	0.9	1
	Bisexual	6.1	7
	Other	1.8	2
Age Group			
	23-29	6.1	7
	30-35	28.1	32
	36-40	28.9	33
	41-45	26.3	30
	46-50	4.4	5
	51-67	5.3	6
	Missing	0.9	1
Race			
	Asian	2.6	3
	African American	3.5	4
	White	91.2	104
	Other	2.7	3
Hispanic			
	Yes	6.1	7
	No	93.9	107
US Region of Residence			
	North East	29.8	34
	South	28.1	32
	Mid West	21.9	25
	West	19.3	22
	Missing	0.9	1
Marital Status			
	Married	86.0	98
	Divorced	4.4	5
	Widowed	1.8	2
	Cohabiting	1.8	2
	Single/Never Married	6.1	7
Education			
	High School Graduate/Diploma or Equivalent	2.6	3
	Technical School Degree	0.9	1
	Associate Degree	3.5	4
	Bachelor's Degree	27.2	31
	Post Graduate Degree	61.4	70
	Professional Degree	4.4	5
Employment Status			
	Employed Full-Time	73.7	84
	Employed Part-Time	14.9	17
	Unemployed	5.3	6
	Student	2.6	3
	Other	3.5	4
Religious Preference			
	None	43.0	49
	Protestant	11.4	13
	Catholic	20.2	23
	Jewish	5.3	6
	Other	13.2	15
	Missing	7.0	8

SUMMARY DATA ON PARTICIPANT REPRODUCTIVE HISTORY AND MEDICAL EXPERIENCE

The average age of participants at the time they first sought medical assistance was 32 years of age, with ages ranging from 21 to 42 years. The majority of the participants had between one and three pregnancies in their lifetime (86%). The maximum number of pregnancies reported was seven with a sample average of 2 pregnancies. Approximately 63% of the sample had one pregnancy that resulted from the use of medical assistance, another 24% had two pregnancies and 11% had three pregnancies as a result of medical assistance. One half of the sample experienced spontaneous pregnancy loss due to a miscarriage or an ectopic pregnancy. Slightly less than five percent experienced the loss of a child during labor, birth, or in the early days after birth.

TABLE 3.2: PARTICIPANT REPRODUCTIVE HISTORY & MEDICAL EXPERIENCE			
Variables		**% / Avg.**	**N / Range**
Age 1st Sought Med. Assist.			
	21-29	28.1	32
	30-35	52.6	60
	36-42	19.3	22
Type of Med. Assist.			
(Select all that apply)	Intra-Uterine Insemination (IUI)	64.0	73
	In-Vitro Fertilization (IVF)	64.0	73
	Gamete Intrafallopian Transfer (GIFT)	0.9	1
	Zygote Intrafallopian Transfer (ZIFT)	0.9	1
	Artificial Insemination	14.0	16
	Fertility Medication	57.9	66
	Other	13.2	15
Used Donor Sperm	-	21.1	24
Used Donor Embryo	-	6.1	7
Embryo in Storage	-	35.1	40
Met Medical Infertility	-	77.2	88
Infertility Diagnosis & Treatment	-	36.8	42
Seeking Treatment	-	12.3	14
Insurance Coverage			
	Yes	42.5	48
	No	57.5	65
	Missing	0.9	1
Financial Assistance			
(Select all that apply)	Loan	8.8	10
	Personal Funds	66.7	76
	Other	13.2	15
Lifetime # of Pregnancies	-	2.3	1-7
# of Pregnancies with Med. Assist	-	1.5	1-6
Spontaneous Pregnancy Loss	-	50.9	58
Pregnancy Loss	-	4.4	5
Future Desire for Children			
	Yes	43.9	50
	No	29.8	34
	Unsure	26.3	30

As shown in table 3.2, intrauterine insemination and in-vitro fertilization were the two most common types of medical assistance used by approximately 64% of the sample respectively. About 14% did artificial insemination and approximately 58% of the sample took some form of fertility drug. Only 6% of the sample used donor embryo while about 21% used donor sperm during their successful treatment. Approximately a third of the sample (35%) had embryos in storage at the time of the survey. When it came to future desires to have children,

44% of the sample wanted to have another child at some point in the future with another 26% of participants who were unsure about their future childbearing decisions. A small percentage (12%) of participants were engaged in the process of seeking treatment at the time of the survey. In response to the question, "Was there ever a time when you were trying to get pregnant but did not conceive within 12 months?" approximately 77% indicted yes, but only 37% have ever received a diagnosis or treatment for a condition that prevents pregnancy. Women reported having anywhere between 1 and 38 combined medical attempts. Two thirds of the survey participants indicated that the financial costs of medical procedures were covered either partially or in full with personal funds (67%); others were assisted by health insurance (42%); used a loan (9%); and/or some other monetary source (13%).

V. OVERVIEW OF ANALYTICAL STRATEGIES

Chapter 5 is the only data chapter based entirely on quantitative analyses. Related to the second research objective specified on page 3 to exam differences in attitude towards conception disclosure, the questions guiding this chapter are as follows: *1) What are the underlying dimensions of disclosure attitudes about assisted conception? 2) Are there differences in disclosure attitude or behavior based on sexual identity? 3) What factors predict conception disclosure to the child?* To answer these questions, I used a factor analysis to summarize the data and determine the interrelationships between 18 items concerning attitudes towards disclosure about having used ART. There have been a number of reasons for and against disclosure about conception highlighted across research in the area (see Chapter 2). My objective in this analysis is to determine, using a factor-analytic technique, the most significant and smallest number of explanatory factors considered when making disclosure decisions. I used a reliability analysis, along with other techniques, to validate the scales and determine goodness-of-fit for the different

tests (f*urther details discussed in Chapter 5*). Two dimensions were identified and labeled care motivated disclosure and fear motivated non-disclosure. Differences on the two dimensions based on sexuality at the bivariate level were examined using a T-test while differences in disclosure behavior were determined using a chi-square test. Significant differences were observed on one of two extracted factors as well as on a number of disclosure behaviors across family and friendship networks.

In Chapter 5, I also examine what factors predict the probability of disclosing conception information to children. I used a logistic regression to predict disclosure behavior based on sexual identity, controlling for select variables. The dependent variable used in this analysis is based on the question, *"Have you disclosed to your child(ren) about how they were conceived?"* with response options "yes" or "no." The predictors included in the model are sexual identity and a select few socio-demographic variables: age; race; marital status; employment; and education. Based on the literature, I also included number of children conceived with medical assistance; use of embryo or sperm during successful treatment; the experience of infertility over a 12-month period and the diagnosis of any medical condition that causes infertility. I, therefore, examine the probability of disclosing to children as a product of socio-demographic variables and aspects of an individual's reproductive history based on the logistic equation below:

$$\ln\left[\frac{\hat{p}}{1-\hat{p}}\right] B_0 + B_1X_1 + B_2X_2 \ldots B_KX_K$$

Ordinal level independent variables were dichotomously coded for inclusion into the model (analytical strategies are detailed in Chapter 5).

For the purposes of these analyses, I used the IBM SPSS Statistics 23 under a licensed subscription by Syracuse University. The level of confidence for the purpose of this research is 95% ($\alpha = .05$). As a general approach to all statistical analysis, persons were dropped from the

analysis if missing on the dependent variables. For the purposes of the logistic regression, I used a mean or mode imputation to handle missing values on independent variables. This approach is justified on the basis that across all analysis, data was missing on a small proportion of the sample (generally less than 5% of observations).

Chapter 4 examines the fertility patients' experience within the medical encounter. Consistent with the first research objective specified in Chapter 1 to explore fertility treatment experience, the research questions guiding this chapter are as follows: *1) How do individuals undergoing fertility treatment experience the medical encounter? 2) Does the experience within the medical encounter vary based on sexual identity?* Related to the second overall research objective, Chapter 6 discusses the importance of disclosing conception information with children and the research questions guiding this chapter are as follows: *1) Are there differences in the perceived importance of disclosing to offspring about their conception between heterosexual and sexual minority identified persons? 2) What are the factors that inspire disclosure to offspring? 3) Do these factors differ on the basis of sexual identity?* Also, consistent with the second research objective specified on page 3, Chapter 7 discusses the experience of disclosing to children about their conception as well as future intentions among those who were yet to engage in conception talk with their children. The research questions guiding this chapter's analysis are as follows: *1) Among those who have disclosed what are the strategies employed? 2) Among those who have not disclosed but who intend to, how do they plan on doing so? 3) Are there any differences based on sexual identity in disclosure or planned disclosure strategies?*

The analyses for the qualitative **Chapters 4, 6, and 7** followed a general inductive approach (Thomas 2006). Responses were organized by questions and copied to a separate file with the accompanying participant characteristics. At the beginning of the analysis phase, I

systematically read and reread participant comments to get an overall sense of the sentiments. During the coding process, I used short phrases as labels primarily to synthesize, organize, and manage the data. I subsequently did a more focused reading to identify broad themes based on those short phrases or labels that were consistent across the comments provided by participants. Guided by the research questions, I developed broad thematic areas and conceptual categories accompanied by carefully extracted quotes. I further explore differences based on sexual identity within the thematic areas that emerged and were consistent with the main research objective. This stage necessitated another close reading of the data cross referenced with other identifiable participant information primarily sexual identity, but also including race/ethnicity.

It is important to note that the survey comments highlighted in the data chapters are taken verbatim including abbreviations as well as grammatical and spelling errors. Additionally, most remarks are shared in their entirety to preserve the authenticity of what are on average succinctly written stories and explanations. In order to make the most of the data, quotes shared within each analytical chapter typically represent a different survey participant. In other words, no one participant is referenced more than once unless explicitly stated in my discussion and analysis.

VI. STUDY LIMITATIONS

Overall, my research contributes significantly to our understanding of the experience of assisted conception as well as disclosure attitudes and practices. In particular, it adds to conversation about medical conception and sexuality. Notwithstanding its significant contributions, it is not without some limitations. My dissertation research utilized a sample based on a non-probability technique and as such, the findings discussed in this document and any publications that may develop from it are not generalizable. Furthermore, because persons self-selected into the survey, there is the potential of a sample selection bias; the persons who opted

into the survey may differ in characteristics and behavior from those who did not participate. For instance, persons who participated in the survey appeared to be well informed about treatment processes and were active agents in their fertility experience. Participants consistently provided recommendations to future fertility treatment seekers that encouraged researching treatment options and active participation. This may serve to indicate then that the persons who participated in the study might be more vocal, potentially more resourceful, and more capable of advocating for themselves. Likewise, the experiences within the medical encounter among individuals who successfully conceived might differ substantially from those for whom the technology has failed. Since computer, internet, and email restrict participation to those with access, this introduces additional sampling bias.

Given that the population of persons who have used assisted reproductive technologies is unknown, sizeable and geographically spread, it was impossible to target specific individuals. As a consequence, the survey was open and available to anyone who desired to take the survey and who was among the intended audience based on their own determination. This presents at minimum three challenges. For one, aside from judging the authenticity and logic of the responses provided, it is a challenge to determine if the participant in fact fit the criteria of the study. Secondly, the responses might not reflect the experience or opinion of the actual person who used assisted technology, but might be a third party/proxy interpretation. Third, persons can technically complete the survey more than once providing they do so using a different computer or same computer with different IP (Internet Protocol) address.

Another important limitation of this study is that it relies on retrospective data. A number of questions included on the survey rely on recall memory and therefore carry the risk of a recall bias or error. Based on the literature, however, infertility and the use of assisted reproductive

technologies to conceive are significant and memorable life events and for that reason I anticipate accurate approximations or representation of the process and experience.

Internet surveys are also plagued by low response rates. In this research, sample size limited the use of more complex multivariate techniques. Additionally, given the sample is overwhelmingly white, highly educated, and largely heterosexual identified, there are some nuances and patterns of behavior and experiences that might be less discernible. In this regard, my analysis is limited by homogeneity within my sample. A more diverse sample based on race/ethnicity, sexual identity, socio-economic background, and cultural capital will expand our knowledge about access to reproductive technologies, the experience undergoing treatment, and mechanisms of support.

VII. CONCLUDING THOUGHTS

This chapter outlined the methodological and analytic approaches utilized in my research. Since chapters differ based on analytical approach, more details are explained in each respective chapter. In this chapter, I highlighted some of the limitations of my research methods since they provide some insight and framing for the analytical approach as well as interpretation of the data and findings.

What remains are four data chapters based on quantitative and qualitative analysis. Each chapter includes additional information on analytic approach as well as the results and discussions. At the end of each chapter is a concluding section, however, the final chapter (Chapter 8) of this dissertation includes a more global discussion and conclusion as well as possible future research developments.

CHAPTER 4

THE FERTILITY PATIENTS' EXPERIENCE WITHIN THE MEDICAL ENCOUNTER

I. INTRODUCTION

Based on the medical definition of infertility, most individuals who seek treatment do so after prolonged periods of trying to conceive naturally. For most, the clinic is a pivotal site; a symbol of hope for those wanting to become pregnant. Allan (2007) describes the clinic as a "liminal space where periods of limbo and transformation can be tolerated, while at the same time a medical space that creates more ambiguity and uncertainty" (p.132). Uncertainty due precisely to lengthy treatment schedules, low success rates as well as undiagnosed or misdiagnosed conditions, which leads to an indeterminate state of waiting to become pregnant. For example, studies suggest that waiting to find out how many eggs had fertilized or to determine success of embryo transfer, loss of pregnancy, and the aftermath of failed attempts were among the most stressful aspects of IVF (Connoly et al. 1993; Hammarberg et al. 2001). Besides what the space itself represents in theory, the technicians and their technologies significantly and actively shape individuals' experience of fertility treatment, irrespective of success.

When it comes to the medical encounter for fertility treatment, studies have been attentive to quality of care, treatment experiences as well as factors associated with discontinuation and termination of fertility treatment (Akyuz & Sever 2009; Dancet et al. 2011; Hammarberg et al. 2001; Redshaw et al. 2007; Van den Broeck et al. 2009). Scholarship tends to focus on organizational factors, that is the clinic environment, as well as physician and staff attributes. Moving beyond the experience at the level of the organization, this chapter highlights the perspective of the patient. More specifically, I present a structural analysis of the experience

of fertility treatment with the view that the clinic, its staff, and physicians are part and parcel of a system of power within medicine. Therefore, their actions and the experience of patients within this setting cannot be analyzed independent of this historical context of medical dominance and physician control.

This chapter adds to research on treatment experience and discontinuation which otherwise present patients as waiting to be choreographed, passive recipients of healthcare. As discussed in Chapter 2, medical discourse concerning fertility treatment discontinuation is tied to efforts to establish more patient-centered care ultimately to aid retention. The discussion within this body of work often draws distinctions between patients who are compliant and those who are non-compliant. Notions of choice, agency, power, and reproductive control tend to be absent from the analysis. In this chapter I use a conflict theory perspective to examine these issues pertaining to power relations within the medical encounter. In addition, I use a feminist to understand women's experience undergoing fertility treatment and their perception of the technologies. Based on my analysis, I use a medical consumerism framework to present a counter argument to the passive patient discourse, highlighting the ways in which individuals who pursue fertility treatment empower themselves through research, question physician expertise, and demand inclusion. In this chapter I answer the following research questions related to my first research objective: *1) How do individuals undergoing fertility treatment experience the medical encounter? 2) Does the experience within the medical encounter vary based on sexual identity?* I qualitatively examine these differences based on responses to a set of questions that asked respondents to: describe their overall experience seeking medical assistance to achieve pregnancy; whether they have changed a fertility clinic or doctor and the reason for doing so; and finally, to provide any advice to persons seeking treatment. Participants drew connections

between the questions particularly in this section concerning clinic and fertility treatment experience. I, therefore, read across the responses provided on the survey to these set of questions to address the above-mentioned research questions.

The remaining of this chapter is organized into five subsections. The first four subheadings - ART & Medical Uncertainty; Medical Objectification; Structuring Biological Reproduction; and Reclaiming Body Sovereignty - are used to organize the discussion of the experience of the medical encounter for fertility treatment. The final subsection highlights the unique fertility treatment experiences among a relatively smaller sample of sexual minority individuals who participated in the survey. Survey comments are a synopsis of participants' experience based on what they recall, as well as what they were willing to and took the time to share. I have therefore included most quotes in full script to provide context and preserve the authenticity of the participants' survey comments.[9] Full quotes allow the reader to see the complexity and multiplicity of experiences within the medical encounter for fertility treatment. For larger quotes, I have bolded sections to focus the reader's attention on parts of the participants' comments that are germane to the discussion.

II. RESULTS

ART & MEDICAL UNCERTAINTY

Medical uncertainty manifests itself in different forms during the course of fertility treatment. A lack of plausible explanations and indeterminate outcomes which prolonged treatment attempts are among a number of examples cited by participants in my study. As a consequence, women questioned the exact scientific nature of assisted conception and discussed successful outcomes as a game of chance. Indisputably, medical conception requires skills and a

[9] Quotes have been included verbatim to include all misspellings and grammatical errors.

high degree of knowledge, however the guarantee that one expects from biomedical technologies is sometimes unmet.

The psychological, physical, emotional, and financial burden of infertility is well documented. For most, what constitutes the burden is the ongoing struggle to determine the cause of infertility and the process of resolving it. When asked about the reason for discontinuing treatment with the clinic, a Hispanic white lesbian identified participant commented, *"was there a year and nothing happened and they didn't have any new ideas or suggestions."* Determining the cause of infertility took several attempts and procedures for a non-Hispanic white heterosexual identified participant who wrote:

> *I was exhausted by the testing, and the fact that the testing always seemed to reveal something new to treat. It required multiple surgeries to deal with my endometriosis, in addition to medications... not to mention a pile of precautionary procedures that sometimes seemed a bit unnecessary (e.g. a brain MRI, an HSG, a uterine scope, accupuncture [sic], etc.)…*

Similarly, for several women the process of fertility treatment was lengthy and did not follow a linear trajectory from treatment initiation to a successful pregnancy. When asked about the overall experience, one non-Hispanic white heterosexual identified survey participant commented:

> *It was incredibly difficult. We had three failed IVF cycles with my eggs, then another failed cycle using my sister's eggs. It was a terribly hard decision to use an egg donor, and even then, we didn't know if it would work. I'm so glad it did, but those 4 years trying to conceive were the hardest I have ever known.*

Another Hispanic white heterosexual identified participant described undergoing 4 IUIs before successfully getting pregnant using IVF. She further stated that she had "*unexplained infertility which often makes treatment a shot in the dark."* The numerous attempts to arrive at a successful outcome and her shot in the dark reference further illuminate the improbable nature of fertility treatment.

Incompetence and (mis)diagnosis, although not explicitly stated, were motifs in many participants' stories. These experiences addressed the mismanagement of infertility, which highlighted the shortfall of medical expertise. Take as an example, the following comment from a non-Hispanic white lesbian identified participant, which concerns faulty diagnosis and the questionable quality of medical expertise with respect to fertility treatment:

> ***After several IUIs did not result in a pregnancy, the nurse practitioner recommended a hysterosalpingogram to make sure that my fallopian tubes were clear and also they scoped my uterus. The nurse practitioner left a message saying that there were suspiciouos [sic] lumps in my uterus and I should make an appointment for a D & C with a biopsy, but when I called to make the appointment, I was told that the nurse practitioner no longer worked there and they were not seeing her clients****. So I guess I didn't make the decision [to change doctor]--it was made for me. However it was a very good decision.* ***When I went to my new doctor with the list of medications that had been prescribed and everything else, the new doctor was shocked at the poor level of care, including stopping and starting fertility medications in very problematic ways.***
>
> *My situation was very unique in that I conceived triplets through insemination.* ***Upon medical advice I had s procedure that ended up in the loss of the entire pregnancy. In addition I was hospitalized for a week due to sepsis that occurred during the procedure***

after recovering physically and emotionally I went to a new facility and Doctor and underwent 2 successful IVFs, resulting in 2 beautiful children.

For the non-Hispanic white heterosexual identified participant above, treatment inconsistency and a lack of medical expertise resulted in the traumatic loss of a pregnancy and further medical complications. A non-Hispanic white heterosexual identified participant described an experience that involved three physicians, one of whom gave problematic testing results and downplayed her chances of conceiving after several failed attempts. She extolled the third doctor for his great work and credited his success to the fact that he and his wife had also conceived through ART.

Three different doctors treated me. The first was a referral from my OBGYN. She was a very well trained, prestigious doctor, but after three failed TI cycles w [sic] injectibles, we saw less and less of her at each appointment. We felt that she wasn't invested in our success anymore. / The second doctor was affiliated with a prestigious clinic. We attended their informational seminar and immediately after attempted our first IVF cycle. It was not a good experience. The doctor did all of the monitoring appointments for all of his patients himself, and had all of his patients on the same cycle start date, so we experienced one hour wait times for every monitoring appointment. ***Then when we would report his follicle measurements they were inconsistent and confusing. He ended up retrieving five eggs, three of which fertilized, but none grew into embryos. He immediately insisted on donor egg as our next step and was very negative about our chances of conceiving with my own eggs.*** */ / The third and last doctor was our answered prayer. He is to date THE best doctor I have ever had. He and his wife personally experienced IF together and conceived both their children with ART. He had*

incredible bed-side manner, communication skills, and a level of empathy rarely given from medical professionals. He led us to our baby and I will never, ever forget him.

This larger excerpt above highlights a number of issues including impersonal treatment, lengthy treatment procedures, scheduling, poor standards of care, and complicated prognosis. This is a model example of the complexity of the treatment process for many. These complexities are reflected both in my data and several infertility experience blog posts which address the difficulty finding a doctor and some medical complications that ensue from medical mismanagement of fertility treatment.

As a consequence of the aforementioned experiences, participants disregarded assisted reproduction as a true form of medical science. One non-Hispanic white heterosexual identified participant commented, *"Extremely frustrating experience becuase [sic] it is still art not science. It is an emotional rollercoaster and every failure is extremely personal with a feeling like you want to die on the spot."* Another Black/African American heterosexual identified participant similarly commented, *"it's an art, not a science, so don't go thinking you'll find the smoking gun that explains why it was tough before."* The juxtaposition of art versus science conjures the idea that if science is about the systematic gathering and organization of data, objective analysis, and assured results, then assisted reproduction is not that. Consistent with this viewpoint, participants mentioned their experiences with lengthy treatment protocols, frequent testing, and numerous procedures - most of which failed. Additionally, patients recounted experiences of medical negligence accompanied by grave consequences such as involuntary termination of pregnancy.

Fertility treatment is experienced as a game of chance with randomized outcomes. Thus, *lucky* was a frame used by several participants to describe their experience, whether they were referring to having access to ART, the treatment process, or successful conception. One non-

Hispanic white heterosexual identified participant commented, *"I consider myself lucky that I knew IVF was necessary for pregnancy prior to thinking about conceiving so we did not have to go through the process of unsuccessfully trying and wondering what was wrong."* An early successful outcome was never explicitly accredited to the medical technologies. Instead, participants, who recognize the process can be lengthy and invasive with no guarantees, felt lucky that their issues were resolved quickly. "*Again, I was very lucky. Because my level of inability to conceive only required IUIs plus Clomid to conceive"* (non-Hispanic white bisexual identified participant). While one non-Hispanic white heterosexual identified participant gained trust in medicine, she still acknowledged the role of luck in her experience, "*I have new faith in medicine after my pregnancy but I realize I am one of the lucky ones and in a minority."* Another non-Hispanic white heterosexual identified participant commented, *"Amazing experience and so lucky to have my son on the first attempt."*

Fertility treatment is a dynamic process and a lack of scientific certainty concerning a successful outcome creates more anxiety and raises skepticism about medical competencies. Frequent, repetitive, and sometimes ineffective testing were common experiences survey participants highlighted, which potentially diminished overall perceptions about the efficiency and effectiveness of the medical treatment of infertility. As stated by one non-Hispanic white heterosexual identified participant commented, *"I am happy it worked, but many times I felt like the doctor was just guessing. The doctor was not very personable or understanding about the emotional stress we were going though."* Interestingly, terminologies used in participants' description of their fertility treatment experience included luck and guessing as well as referring to the process as unscientific, are not typically associated with science or medicine. These were however, the frames used by participants in their analysis of the experience of fertility treatment.

The medicalization of infertility, like many other areas within medicine (psychotherapy as well as obstetrics and gynecology) continues to effectively convert persons into "serviceable objects," claiming specialized knowledge to cure such things as infertility (Armstrong 2000). Individuals therefore embark on the journey for fertility treatment with the expectation that they will be cured of whatever condition that is causing their infertility. The journey for many women who participated in the survey and who achieved success was bumpy, emotional, life altering, more like a rollercoaster ride along new unchartered territory. There are still yet a significant group of individuals, not included in this project, with unresolved fertility issues and who concluded treatment without success. Fertility treatment does not guarantee a positive outcome, but is a probabilistic dance under the right conditions between some known factors, experimentation, and a stroke of luck. One would expect that since individuals who pursue fertility treatment are more motivated that they would have greater confidence in medical technology. However, the individuals who participated in this project were critical of the process due to some unfavorable experiences.

MEDICAL OBJECTIFICATION

Scholars have long characterized the practice of medicine as one that objectifies patients and the medical encounter as one dominated by conversations about symptoms of ill-health. Human anatomy – function, failure and restoration – is a physician's preoccupation, distinct from the social. Reproductive medicine is not divorced from this practice of separating the body and the person or reducing individuals to the mere function of their reproductive bodies. To borrow a terminology from Tjornhoj-Thomsen (2005), the fertility treatment process creates a "fragmentation (of selves and bodies)" (p.87).

From the perspective of the women who participated in the survey, the experience of fertility treatment is depersonalized, regimented, and homogenized. Approaches in medicine, and in particular reproductive medicine, are established based on standardized protocols and statistically validated success rates. As a consequence, the process tends to follow predetermined processes and is less flexible in meeting individual needs. One non-Hispanic white heterosexual identified participant commented, "*He had a set of routine exams, procedures and tests that he did and then a set list of medications to prescribe. I had a terrilbe [sic] reaction to the meds and found him to be very cold and uncaring."* A loss of individualism was a significant aspect of patient experience of fertility care. For the individuals who must take the biomedical route, the treatment process followed more of a one-size-fits-all solution and felt anything but personal. One Black/African American heterosexual identified participant commented:

> *First clinic I used wanted to continue same course of treatment with no variations (medication only) for 5 months. even after we expressed interest in trying IUI or iVF [sic]. Also, I saw the doctor only one time over a 5 month period. Doctor was based in another city and only visited this office occasionally. Treatment was done by ARNP.*

The above comment from this participant indicates that she was placed on auto-pilot despite an expressed desire to deviate from the established treatment blueprint. It was simply not allowed.

Consistent with the understanding of medicine as objectifying and dehumanizing, participants provided some evocative comments that raise issues about being experimental subjects, objects, just a number, or a product on a production line. In the following comment, this non-Hispanic white heterosexual identified participant described her initial experience as impersonal, systematized and normalized:

> *The first clinic I went to was not the one recommended by my OB/GYN. I had a terrible experience with the physician and a procedure he performed on me.* ***I was not comfortable with him and I did not feel like an individual patient but more like a a [sic] subject placed into a category and given the same treatment plan as others when I needed specialized testing and medication.***

In essence, participants experienced many instances where they felt that their body was the nucleus of the encounter and that there was no care or consideration given to them as a person. Others described feeling like an object or something akin to experimental subjects who were under "treatment regimes" dictated by the physicians (Redshaw et al. 2007:298). One Black/African American heterosexual identified participant commented, *"I changed because I felt like I was just a number (money) to them. Each month it was the same process without any further investigation into the possible causes."* Another non-Hispanic white heterosexual identified participant commented: "*The first clinic I went too was impersonal. I did not ever feel like I was anything more than a lab rat. I also didn't feel like my questions and concerns were being answered or met."* The feeling of being invisible as a person accounted for the reason why several of the participants in the survey changed clinic or doctor. In the following comment this Hispanic white heterosexual identified participant used a manufacturing metaphor to describe the experience within the medical encounter for fertility treatment: *"No personal attention to my specific medical history. Felt like I was given the standard course of treatment not specific to my needs. Patients were treated like product through a conveyer belt."* Another non-Hispanic white heterosexual identified participant commented, "*I felt like a number and not a patient that was cared about. Because I felt like the doctor was very impersonal. Research and find the facility*

with the best lab. The first few years were disappointing, but once I found the preferred clinic, I was overall pleased."

The production line approach to reproductive medicine applied both to individuals with and without "biomedical barriers to fertility" so long as they were seeking fertility treatment (Johnson & Simon 2012:265). Individuals who identified themselves as LGBQ underwent the same routine treatment as did heterosexual couples with medical infertility. Take as an example the comment below from a non-Hispanic white lesbian identified individual, who even with prior attempts to conceive, still did not meet the medical definition for infertility but was subjected to the same course of treatment (prescribed for everyone).

> *…Going through it, it was difficult. We had been doing unmedicated, at-home inseminations over the course of 8 months (only 4 ICIs) by the time we switched to a clinic.* ***We did two unmedicated IUI inseminations (2 months) and then did two medicated (small dose of clomid and HcG trigger shot) IUI inseminations (over 2 months).*** *The last (4th) IUI worked…The year of trying to get pregnant was really emotionally difficult. It was really hard when we switched to the clinic and the first IUI didn't work; I got scared that there really was a fertility problem.*

It is evident from this quote that the process of medicalization of reproduction treats any person with the desire to have children and who are unable to do so traditionally, using the same procedures. It is through the process of medical intervention and the failure of such efforts that sometimes inspires one to think there might be a problem.

Many medical sociologists have discussed the medical encounter as one that is fixated on the body and symptoms of illness. This practice has the tendency to marginalize the person in the medical encounter. The physician is expert of the body, the technician, the service man who in

the medical encounter uses his expertise to fix the infertile woman and who infrequently accommodates her thoughts or feelings. One non-Hispanic white queer identified survey participant commented, "*Left the first clinic because the doctor was a mansplaining asshole who thought he knew more about my cycle than I did."* In the practice of medicine physicians make no room for patients' lay understanding of their body, illness, causes of ill-health, or treatment. Approaching infertility as a "sick role" requires that the patient seeks treatment from a medical professional, surrenders their bodies, and complies with doctor's instructions (Parsons 1975). The infertile body, as an object of the medical gaze, must be placed under precise treatment regimes, which must also be strictly adhered to by the patient to increase the likelihood of a successful outcome.

STRUCTURING BIOLOGICAL REPRODUCTION

Medicine is both a social institution and a form of social control. In the case of fertility treatment, physicians act as information disseminators and gatekeepers. For the participants in the survey, and persons undergoing fertility treatment in general, physicians define, diagnose, and dictate treatment options. Based on the comments in this section physicians also prescribed solutions that were outside the medical realm; suggesting instead that patients either seek adoption or give up the goal of becoming parents altogether. Research shows that physicians have used patients' personal history to create "symbolic boundaries" and demarcate "less appropriate parent-candidates" (Malin 2003:302-303). Usually in these judgments, race and class are key markers. For example, unfit parents are often from racial and sexual minority groups; economically disadvantaged; and less educated. These groups of individuals are mostly encouraged to use contraception to prevent pregnancy rather than finding ways to improve fertility (Bell 2009, 2010, 2016). For participants in this study, physicians used age and history

of sexual abuse as justifiable reasons to prescribe alternative pathways to parenthood or termination of their efforts altogether.

Medical wisdom purports that delaying pregnancy until older ages is increasingly associated with the risk of infertility and the increased probability of an unsuccessful outcome after using ART. Waiting longer to have children at older ages is associated with several medical predicaments including diminished viability of the eggs and lower probability that the ovaries will release eggs, among other health-related challenges that increase the likelihood of infertility. Age of the mother is therefore believed to be of paramount importance since it influences her overall ability to conceive and the success of the treatment. Achieving and maintaining a reputation for high treatment success might therefore inspire doctors to use age as a key eligibility requirement. A few survey participants recalled being condemned for waiting too long. In response to the question about overall experience a non-Hispanic white heterosexual identified:

> *The doctors all were horrible.* ***They were so focused on my age*** *(which lets face it was not that old) and on invasive options. This was in spite of all my tests always showing I had healthy ovaries that were producing regularly, no obstructions, no problems at all! They really made me mad on a regular basis. I had done plenty of research on my options and knew I wanted to do the least invasive / most natural way of getting pregnant that I could under the circumstances (single). He was constantly pushing for more agressive [sic] (and of course expensive) options* ***and basically telling me that I was to blame for not being pregnant.*** *The only reason I stuck with the doctor I started with was that when I had a second opinion, he was saying the same stuff. I did love the staff in my doctors office so that made it worth sticking with the first one. / / I was pretty surprised that the*

> *doctor I had never asked about my diet / excercise [sic] or other things that may be important to getting pregnant. When I FINALLY went to an accupuncturist [sic], it was such a different experience. She was focused on my whole life - my mental health, my physcial [sic] health, and doing whatever she could think of to help my body do what was needed to have a healthy / successful pregnancy. It still makes me mad to think about what the doctors were saying and how they were so wrong about everything. I just wish I had saved myself so much time and money by going to my accupuncturist [sic] first.*

Failure to subscribe to medically determined timelines for reproduction makes it so that a woman, who deliberately delays childbearing until later years, is directly blamed for her fertility challenges. This practice shifts the responsibility squarely from medical science to the patient and relinquishes the physician of any burden to resolve the patients' infertility. At least one participant internalized this as the reason for her fertility issues. In response to the question pertaining to decisions to change physician, a non-Hispanic white heterosexual identified survey respondent wrote:

> *They were rude, patronizing and the environment was like the DMV. I was appalled by the way the doctor spoke to me as though I was a stupid child--**she assumed no knowledge of human reproduction and told me I had waited too long (which I had) but as time travel hasn't been invented it wasn't much use.** When I went for a day 2 blood test, they sent me to the wrong place to have blood taken with women who were cycling (so I could have been given the wrong test). Reception staff were more interested in looking at their phones and the place resembled a prison, not a clinic linked to an Ivy League university.*

If biological kinship is the desired objective for persons seeking fertility treatment, failure to achieve such an objective naturally and within socially or medically expected timeframes meant they were no longer entitled to such a privilege.

The medicalization of infertility reifies physicians' role as custodians of dominant ideological norms. According to Malin (2003), "symbolic order materializes in medical discourse and practices when the clinician determines who is and who is not given a chance to reproduce with the help of ART" (p.302). The following comment speaks to at least one instance where this non-Hispanic white heterosexual identified participant was encouraged to seek adoption:

> *my OBGYN, who was part of a clinic group (not a standalone fertility clinic), was supposed to be one of the best infertility docs in the area, but he told us that* ***we should get comfortable with the idea of never having children, or we sholud [sic] decide to adopt****. i refused to accept that without further testing.*

Along with diagnosing and prescribing, physicians also function here to regulate socially prescribed roles; helping some to become parents while denying others. Other aspects of a patient's history were used as justifiable evidence for why one should not be a parent. For the following non-Hispanic white heterosexual individual, the experience of sexual abuse rendered them potentially unacceptable parents:

> *consulted with two different fertility doctors/clinics that I felt were unprofessional.* ***One questioned whether I should even be a parent due to my history of sexual abouse [sic] as a child and asked many intrusive questions about this abuse.*** *The other had a staff member leave me mid procedure in stirrups to take a phone call and opened and closed the door from the treatment room to the lobby several times while I was poorly draped.*

In the past, scholars have utilized the concept of "stratified reproduction" to describe the way in which some individuals are encouraged to have children while others are not based on their social location (Bell 2010; Greil et al. 2011). Specifically, race and ethnicity; class; marital status, and sexuality have been primary stratifying variables. Participants in my survey research identified additional variables, including age and other aspects of their social history, such as the experience of sexual abuse. Importantly, these add to our understanding about other elements of stratified reproduction used as mechanisms of control, redirecting patients away from their efforts to establish biological offspring. Deflecting from their inability to fix the problem, physicians made fertility patients the scapegoats for the reproductive challenges they face and attempted to channel them towards other options such as adoption or childlessness.

RECLAIMING BODY SOVEREIGNTY

A fourth dominant theme that emerged from participants' accounts of their experiences in the medical encounter for fertility treatment is what I interpret as an effort to reclaim body autonomy from medical expertise. Participants often advised individuals to educate themselves, do research, advocate for themselves, and be active in their treatment process. Lengthy treatment processes, non-negotiable treatment regimes, unsuccessful outcomes, and unexplained infertility inspired individuals undergoing fertility treatment to act as medical associates. In this role as medical associates, patients actively sought and created collaborative relationships where they could, along with their physicians, examine and determine different treatment options. Participants' self-descriptions presented them as "assertive consumers of medical treatment," who were empowered through research, explored different options, advocated for themselves during the medical encounter, or intentionally withdrew their patronage (Malin 2003:307). The

following two non-Hispanic heterosexual identified participants' comments highlight this relationship between patients' and doctors who collaborate on treatment procedures:

> *it was good - interesting, challenging, exciting - but also very hard.* ***i ran up against my doctor a few times, but he heard me out and sometimes ended up agreeing with me.*** *we did one retrieval and four transfers. i'm scared of needles, so you can imagine how horrible that was. the third and fourth transfers, i did lipid infusions every two weeks. more needles.* ***we were discouraged from doing a fourth round, but we had embryos left, so we felt we should go forward. that round, i chose to do a 'natural' ramp up*** *- no prepping meds, just lots of testing to see when my body did its thing, then a rushed transfer on that day. that last round, with those last two embryos, was responsible for our twins.*
>
> ***Educate oneself. There are many types of treatement [sic], reasons for infertility, etc. When I finally got treatment that helped, it was because I convince the doctor to try immune testing, and after he agreed to it, I had to tell him which tests I wanted, etc****. It was successful (we now have 4 kids), but it took proactive work.*

These individuals employed one of those strategies of medical consumerism identified by Hirschmann (1970) by voicing their desires in order to impact their treatment process (as cited by Rosenthal in Schlesinger 2002). Essentially, some patients were assertive medical consumers, who acted as medical associates and through research, avail themselves with the information necessary to make sense of the treatment process and who utilize that knowledge to influence their own course of treatment. Such an approach to fertility treatment and medical care in general is antithetical to the long-standing view of the patient as a passive consumer who is compliant

and silent during treatment. These women took a more collaborative approach to find or create a balance between the individual's needs and the doctor's treatment plan.

The proliferation of available information on the internet and increased access to such information, has helped significantly in empowering persons to be their own advocates. Consider the following comments left on the survey that encourage individuals to do their research, educate, and advocate for themselves. Participants also commented that persons undergoing treatment or seeking to do so must be cautious of unsupported evidence and should instead evaluate all options. Take as an example the following comment from a white Hispanic heterosexual identified participant:

> ***You are your own best advocate***. *It is important to learn about infertility, your own diagnosis (or lack of), your prescribed medications, procedures, and* ***question, question, QUESTION***. *You are one of many patients (typically) and doctors and nurses are human. On occasion they make mistakes and any professional worth his/her salt will not be offended by your questions.* ***Educating yourself is key as is standing up for yourself and the quality of your care. If something doesn't feel right, say something, and if necessary, find a provider who is a better listener and more responsive.***

In response to the question about overall experience one Hispanic white heterosexual identified survey participant commented:

> ***2 years of treatment were wasted until I was informed enough to self advocate and tell the Dr. what treatment I needed, once that happened I got pregnant. "I researched my symptoms*** *and knew right away I had PCOS.* ***I went through a few doctors before I found one that wanted to treat it (as opposed to trying things like taking a month of birth control pills and seeing if it would kick my ovulation into gear (it didn't).*** *That*

*was the only hurdle**. I read a lot about the condition and sought out a doctor who would listen to me and prescribe medications that research suggested worked to achieve pregnancy.***

Historically, patients were seen as passive subjects when in medical care. The specialized nature of fertility treatment, combined with strong parenthood desires and the social pressures to become parents would lead one to expect that fertility patients will surrender to the expert knowledge of medicine to achieve pregnancy. While all participants in this study chose fertility treatment as their pathway to parenthood and by so doing subjected themselves to what resembles a clinical trial and medical authority, some followed the prescribed course while others carved out their own path. Although active engagement in the process of fertility treatment was done within clear confines, for example finding a doctor or clinic willing to do a particular procedure, efforts to be autonomous in the medical encounter is noteworthy.

Participants retelling of their experience is a counter-narrative to the narrative of the patient as passive recipient of healthcare. Some participants challenged medical authority and expertise, and empowered themselves to actively determine treatment. I use reclaiming body sovereignty to also discuss patients' agentic actions for example changing doctors and clinics when their expectations were not being met. The discontinuation of service became an important form of resistance to being sidelined in the treatment process and being reduced simply to one's reproductive function during the course of fertility treatment. The efforts to reclaim some power and control should not be taken lightly but should be viewed as an important political act. Again, education and research were critical aspects of this reclamation project. Although the participants themselves do not explicitly state that they were attempting to balance the power in the medical

encounter it is strongly implied in the account of their experiences and advice they gave to others who would embark on the quest toward pregnancy using ART.

UNIQUE EXPERIENCES BASED ON SEXUALITY

Individuals who identified as LGBQ qualitatively provided similar advice to persons seeking fertility treatment. For example, LGBQ participants suggested that hopeful parents carry out research, ask questions, and actively engage in the process. With respect to reasons for discontinuing treatment course with a clinic or doctor, LGBQ participants cited similar issues pertaining to mismanagement of treatment and medical objectification.

Quantitatively, over 90% of the sample never or rarely experienced some form of discrimination due to race, sexuality, or gender identity. Among the individuals who sought services from a fertility clinic (N=98), approximately 43% had changed either a clinic or a physician or both during the course of their treatment. Sexual identity did not emerge as the major or sole cause for decisions to discontinue treatment with either a clinic or a physician or both of these entities. Skewed data and small proportions did not allow me to examine group differences; however, qualitatively there were a few unique experiences among the LGBQ group.

Several scholars have documented the experience of discrimination among sexual minority groups from barriers to legal parenting options to restrictive practices that curtail their access to the means of (re)production (see Chapter 2). Individuals in this group within my own research brought up the issue of discrimination, being misgendered, and overall heterosexism, which the following two quotes exemplify. One non-Hispanic white queer identified participant shared:

> *We trusted our doctor first as being among the best in the field. The nurses and clinic staff were supportive but* ***we were suprised [sic] to come across so many instances of heterosexism--poor word choice for talking about our sperm donor, making***

> ***assumptions about our gender identities.*** *We had straight friends who were patients and felt very connected to the staff and nurses (sent baby pictures after the birth, went back to visit the clinic) and we never felt this closeness.*

Similarly, gender identity issues were brought up by another Black/African American gay identified participant who wrote the following comment:

> ***The first doctor I spoke to refused to give me service because of my gender identity.*** *I went to another, friend recommended doctor, and was treated great.* ***I was misgendered at times by 1 nurse and some staff, but they corrected themselves after I corrected them****. The doctor was always great.*

One Hispanic white lesbian identified participant retrospectively accounted experiences that also highlight insensitivity in the clinic setting even when they claimed to be gay-friendly. She wrote, "*they weren't really gay friendly despite having been introduced to the female doctor at the lgbtq center advertising her clinic."*

Fertility treatment has been described as a traumatic experience by many, and for LGBQ persons in particular, the process is precarious at best. Finding a clinic and doctor that offer service to LGBQ people, state laws, cultural insensitivity and navigating a process that has been established for heterosexual couples represent only a few of the issues that they must contend with. One non-Hispanic white bisexual identified participant commented, "*With my first pregnancy, the process was clearly established for heterosexual couples, so much of it was annoying for me and my same sex partner. (They constantly referred to us an infertile. I continually insisted that both of us were fertile; we just didn't have any sperm!) The staff clearly recognized the poor fit of their process, but felt they had to follow the procedure anyway."*

Another non-Hispanic white lesbian participant noted that they were subjected to psychological

assessments and made to do additional tasks as same-sex couples that were not required of their heterosexual counterparts. Although embarrassed by this requirement, they capitalized on the opportunity to educate the staff about how to treat same sex couples:

> *We really pushed the limits of our clinics thinking. We were regularly asking for things they had never thought of. We regularly told them how they could be more accomadating [sic] to same sex couples. / for example - they made us meet with a psychologist because we were using donor sperm - it was embarrasing [sic] and discriminatory as not every individual using fertility treatment had to meet with a phsycologist [sic]. The assumption that using donor sperm meant that we needed counseling was frutstrating [sic]. I believe the facility has changed the policiy [sic] since then.*

While these examples are few, they are not to be overlooked. Indeed, they are consistent with many previous findings (see Chapter 2).

The common thread running through these experiences is the lack of recognition of the difference between persons in heterosexual partnerships and those in same-sex relationships as well as the insensitivity that became a part of the experience. One Black/African American lesbian identified participant commented:

> *Overall it was positive.* ***Loved my own doctor and was very comfortable with her. Struggled more when she was not available when I was ovulating and I had to have other doctors who seemed less thoughtful about how me and my family differ from straight people.*** *After my first child, I tried to get pregnant again, but was unsuccessful. Eventually the stress (disruption of routines for inseminations when it worked for my body but not my work calendar and constant wondering if it worked, finding out it didn't,*

and then starting over) was too much so I decided I could be happy with my family as it is.

To this point, persons will argue that in most instances, sexual minority individuals demand similar treatment, inclusivity, and non-discrimination. In other instances, however, and particularly as it regards fertility treatment, it is necessary to remember that individual needs are different. Stated differently, couples in same-sex relationships face unique challenges to infertility than persons in heterosexual relationships.

III. DISCUSSION

This chapter explores the experience of the medical encounter among individuals who have successfully conceived and given birth to at least one child. Although the individuals in this study all achieved their ultimate goal, they were still critical of the physicians, clinic staff, and the overall process of fertility treatment. Rigid treatment protocols caused patients to feel objectified, while excessive testing, mismanagement of fertility treatment, and failed attempts, lead to skepticism about medical expertise. Participants had either medical or social infertility and intentionally sought medical assistance to find solutions for fertility challenges, yet the treatment conventions and technologies showed no distinction. Additionally, some individuals were chastened by physicians for waiting too long to have children. As if the experience of infertility was not already stressful, participants in the survey experienced shaming during the course of their treatment due to some aspect of their personal history. Notwithstanding, participants proved to be assertive, informed, and active during the treatment process.

Based on my research data, medical uncertainty significantly impacted how patients experienced medical care. Instances of unresolved infertility, spontaneous pregnancy after

treatment termination, as well as lengthy and frequent treatment (with/without success), call into question medical expertise. According to Fox (2000):

> *Uncertainty complicates and curtails the ability of physicians to prevent, diagnose, and treat disease, illness, and injury, and to predict the evolution and outcome of patients' medical conditions and the results of the medical decisions and actions taken on their behalf…Medical uncertainty raises emotionally and exis-tentially charged questions about the meaning-fulness as well as the efficacy of physicians' efforts to safeguard their patients' well-being, relieve their suffering, heal their ills, restore their health, and prolong their lives" (p.409).*

Medical uncertainty prolonged periods of trauma associated with unexplained infertility, pregnancy loss, internalized feelings of fault, and the overall physical as well as emotional burden of the treatment process. Medical uncertainty or the limits of expert knowledge cause patients to be subjected to experimental, extended and invasive treatment plans. As a consequence, patients in my study became critical, assertive and astute participants in their treatment process. In one Finnish study, however, IVF physicians explained that nature, which is the "psychosomatic female bodily reactions that affect… reproduction processes," accounts for inconsistences, uncertainty, and surprises (Malin 2003:311). Attending to this kind of rhetoric is significant for three related reasons. First, it shifts the blame for any lack of medical resolution from the failure of science, medicine, and technology to nature or rather the failing of the female body. Second, it destabilizes medical expertise and authority. Lastly, it corroborates participants' claim that fertility treatment is not a science, but an art involving luck, coincidence and speculation.

Studies suggest that physicians utilize metaphors to describe experience, the function of the body, diagnosis, and treatment. According to Hanne (2015), "Modern Western biomedicine is organized around a series of basic metaphors: the body as machine, the body as the site of battle, and the body as a communication system" (p.35). According to Martin (1987), "the body as machine" metaphor and other production line references have been a central part of medicine since the beginning of medical, scientific, and technological advancements (p.54). Metaphors were similarly used by participants in my research such as lab rat and subject, which are classic terminologies associated with experimental trials while object and products are commonly used in the manufacturing and commercial industries. Importantly, these references symbolize the relationship between physician and patient in which the patient is expected to be a docile body.

Scholars have examined race and social class difference in access to fertility treatment. In addition, researchers have employed the concept of stratified reproduction to discuss mostly a race and class based determination of who is considered to be fit to parent and who is not. My data suggest that age is also a significant factor in this attempt by medical practitioner to control and influence who become parents. I argue that age is critical factor in physicians' attempts to structure biological reproduction because of its significance in determining treatment success. Returning to the Finnish study referenced earlier, physicians negatively remarked about the social experience of being an older mother (Malin 2003). My data also demonstrate that other aspects of one's social biography, such as the experience of sexual abuse and sexual identity, can be used as exclusionary factors when trying to become a parent through ART.

Feminist scholars have long theorized about the relationship between women and reproductive technologies - from contraception to those that aid in conception and reproduction. For many, ART affords individuals, who otherwise were unable to reproduce naturally (because

they were single, lesbian/gay, transgender, or persons with disability, for example), the possibility of conception. Drawing insights from feminist scholarship, I argue that fertility treatment is a choice made against other options and is liberating (especially if successful) for these individuals who are either socially or medically infertile. Although not highlighted in my research data, I concede that fertility treatment may be precipitated by internalized social pressures to become mothers which still persist. Still, recent scholarship suggests that there is a burgeoning group of women who resist this social expectation and who are voluntarily childfree (Doyle et al. 2013; Graham et al. 2013). For these reasons and given the breadth of what participants had to endure during their fertility treatment experiences - physically, emotionally and mentally - as well as the associated costs of treatment, I view these individual efforts to conceive with the help of the technologies predominantly as intentional, self-motivated, and agentic.

One feminist perspective is that what appears to be reproductive liberty and autonomy is really a disguised effort to oppress and subordinate women. Ultimately, ART reinforce women's social role as mothers while at the same time alienating them from their reproductive bodies (see Chapter 2). Consistent with these feminist ideologies, my data suggest that the patriarchal model of medical dominance is still a feature of contemporary medicine. Participants reported being marginalized, objectified, and overall alienated from their bodies while seeking treatment. Still fertility patients are not passive recipients of fertility care, but instead were astute and empowered in the medical encounter. Participants felt empowered to advocate for themselves, to preserve rights, and control over their own bodies - against a medical system that seeks to structure their lives according to medical and biological timelines and invasive testing. Efforts to reclaim body sovereignty are consistent with a radical feminist standpoint about the need for

women to regain control over their bodies within the medical encounter and in this moment of biotechnological advancement.

The data presented in this chapter mirrors and at the same time extends those of earlier studies. Greil (2002) found evidence that women were critical of physicians, empowered themselves through research, asserted agency by changing physicians when they were unable to influence their treatment process, and created inventive strategies to "work the system" (p.103). My findings are consistent with some of those reported by Greil (2002) with one slight departure. The women in my sample were very deliberate and direct in their attempts to influence their treatment and were less invested in developing creative tactics to exert their power. Individuals who participated in my survey questioned medical authority and voiced their opinion about the course of treatment. One Australian study on the experience of fertility treatment among women who successfully became pregnant similarly described the process of fertility treatment as robotic and standardized (Redshaw et al. 2007). Women in the study felt they lacked control in many aspects of their treatment like many of the participants in my research expressed. However, participants in my study did not surrender to feelings of helplessness, but instead several discontinued treatment with a clinic and/or physician. Others shared examples of how they informed and influenced their own treatment process and by so doing balanced the power within the medical encounter by acting as medical associates. Like the data presented here concerning medical associates, perception of expertise, information sharing, and shared decision making, Wilkes et al. (2009) also found these important aspects of the care experience.

Historically, physicians have been positioned as experts of the body while relegating patients' personal experience to lay knowledge. In the era of medical dominance, patients were perceived as passive recipients of healthcare and expected to surrender to physicians' control.

Scholars have referred to this as the paternalistic model within the medical encounter as opposed to an informed or autonomous decision making model where physicians provide information to the patients who have the ultimate responsibility to determine their treatment option (Charles et al. 1997). More recently, the notion of medical consumerism has been integrated into the lexicon on medicine and healthcare, and challenges the idea that patients are simply passive subjects. Medical consumerism views patients as rational decision makers who through research, evaluation and need, act within their best interest. From a medical standpoint, the patient-as-consumer idea holds patients accountable for their own health and well-being.

Reproductive medicine, although a specialized and relatively smaller field within medicine, is not exempt from a medical consumer culture. Consistent with previous clinical studies, respondents in my survey research suggested that they evaluated costs, location, success rates, and quality of care in their decision to both choose and change physicians and clinics. Many of the quotes included in this chapter are consistent with the basic dimensions of medical consumerism outline by Rodwin (1994). Participants used their voice to promote their own interest and felt empowered to discontinue treatment with a clinic and/or physician for whatever reason and sought alternative elsewhere. Furthermore, participants promoted this behavior by advising persons seeking treatment to do research, to educate themselves, to advocate for themselves, and be active in their own treatment process.

Fertility treatment is costly and therefore accessible to mostly a privileged class of individuals. Self-advocacy is also an associated privilege, which might not be afforded to every citizen – based on socioeconomic class, education, employment, race, sexuality, and marital status. Still there is a group of individuals who depend on loans and insurance to cover the cost of treatment. Accessing these benefits sometimes require referrals by General Practitioners or

OB/GYN, who then act as gatekeepers which can substantially curtail consumer choice. This may further diminish the agency of the client who must then re/evaluate the consequence of treatment drop-out; discontinuation and transfer; or any behaviors that may be considered offensive to the physician. According to Tomes (2001), "Given the historical association of consumer ideologies and movements with middle-class white Americans, the patient-as-consumer approach threatens to ignore the experiences of those economically disenfranchised by virtue of poverty or race – to flatten diversity and to privilege the interests of the affluent" (523). Consequently, deciding to purchase a purse from one store as opposed to another does not come with the same consequences and does not have the same stakes for individuals as it does with fertility treatment. An individual does not simply present themselves at a clinic, pay, and walk out with a baby. The politics of the medical encounter having to do with assisted reproduction is greater than this exchange and is not adequately accounted for by this concept.

IV. CONCLUSION

Medicine is part and parcel of a system of power. Individuals requiring any form of treatment are simply therefore bodies that must be reoriented to function effectively with the help of the expert physician. It is thought, therefore, that the untrained individual does not have the ability to comprehend their own experience. In the 1990s, scholars like Waitzkins argued that the medical encounter was characterized by a physician who took and maintained control and at times subverting any patient discourse around their social experience. Combining feminist ideologies about the threat of medical power and dominance through ART and the medical consumerism framework about desire, choice, and autonomy, I contend that this project is at critical juncture in the discourse on the experience of fertility treatment. Participants sought treatment, and made attempts to balance the power in the encounter by questioning medical

authority and physician expertise; vocalizing preferences and sought the means to fulfil their desires. Despite reproductive medicine being a specialized practice within medicine, participants were no less empowered to act within their best interest.

Including the experiences among sexual minority participants demonstrates that despite the unique conditions of social infertility, they were subjected to the same medical management as those medically defined as infertile. This chapter has engaged in dialogue with feminist theorizing about fertility treatment and established that patients are actively a part of their treatment process. The most prominent advice provided on the survey encouraged those considering and seeking treatment to do research, self-education and self-advocate. The findings here add to the discourse on fertility treatment experiences and the conversation on the effect of reproductive technology on individual agency. I have employed the concept of medical consumerism acknowledging that it is useful in explaining behavior but neglects to consider certain barriers as well as the historical and structural dominance of medicine and physicians which is especially critical in fertility research.

The experience of fertility treatment for many involved extensive and rigid treatment processes that alienated individuals from their reproductive capacities and where individuals were chided for having waited too long to have children. The data shows that individuals do assert agency before and during the medical encounter by making choices that align with their best interest. Participants questioned staff competence particularly after prolonged trails and failed attempts. The power of medicine as a form of social control and as a social institution was particularly salient in those stories where physicians discouraged patients from pursuing treatment or seeking alternatives. Are these experiences different for heterosexual identified and those who identified as Lesbian/Gay or Queer? The data does not reveal any such apparent

distinction. However, individuals from the latter group had some unique experiences as previously discussed in this chapter.

As stated in Chapter 3, this research has a number of limitations and consequently these results must be cautiously analyzed. The quotes here are based on short comments that individuals included on the survey and so might be missing some important contextual details. Also, there was a significantly larger group of participants who identified themselves as heterosexual, which limited more detailed exploration of the differences between groups. In addition, the experiences of the participants in this survey varied across time and space which might explain some decisions and practices. Notwithstanding, the snippets of stories provided by the women who participated in the survey and who shared their experience of the medical encounter for fertility treatment provide incredible insights for individuals seeking fertility treatment. This analysis adds to the conversation on the experience of fertility treatment in many ways. Most scholars have examined experience among women who have used IVF for example, while this project views the treatment process as involving a range of procedures and technologies. Additionally, my research demonstrates that fertility patients are agentic actors even within the very structured process of medical treatment which attempted to treat every body as same.

CHAPTER 5

CONCEPTION DISCLOSURE ATTITUDE AND BEHAVIOR

I. INTRODUCTION

Previous research, which has explored conception disclosure using a variety of survey questions as well as interview data, show that disclosure is influenced by several factors. Reasons for disclosure to children include for example the right of the child to know, creating and maintaining trust, and protecting the child from accidental disclosure (Blyth et al. 2010; Hershberger et al. 2007; Readings et al. 2011). Alternatively, reasons for non-disclosure included that there wasn't a need to tell, it is personal matter, telling makes it an issue, concerns about identity disruption, fear of the way it would impact parent-child relationships, and a desire to protect the child (Applegarth & Riddle 2007; Lycett et al. 2005; MacCallum & Golombok 2007). The factors are many, but could possibly have a basic shared emotion. My approach in this chapter moves away from current methodological practices that measure disclosure as influenced by singular and separate factors, toward the development of a conception disclosure scale. The main objective of this chapter, therefore, is to determine the underlying dimensions of people's attitude towards disclosure and to examine the practice of conception information sharing based on sexual identity.

Disclosure is a complex process involving a number of differently situated stakeholders: parents, children, donors, and an extended support network. This chapter discusses conception information management based on an analysis of questions about parents' choice to share conception information with members of their familial and social network. Conception information management among ART users can be an intricate process of information control and dissemination pertaining to details about how a child was conceived and the circumstances that lead to such course of action. Critical to this process are decisions about who is the custodian

of the conception information and therefore who has the right to share such information (Blyth et al. 2010). Some parents argue that children are the owners of the conception information and therefore have the right to know and disseminate the information as they deem necessary. Others express concern that information sharing threatens family privacy so that once the information has been shared, even to the child, it takes control away from the key shareholders (i.e. parents). This becomes even more problematic for women who see their children's conception story as inextricably linked to their own history of infertility.

Some researchers have been attentive to decisions, intentions and experience of disclosure as well as overall variations in disclosure practices. However, almost all have exclusively focused on children conceived using donor gametes. These studies place emphasis on disclosure to offspring and less so on other individuals. A few studies have explored disclosure to other familial and social networks (Blyth et al. 2010; Hershberger et al. 2007; Readings et al. 2011; Rosholm et al. 2010). In these studies, disclosure to work colleagues, acquaintances, friends, and family members is not the central focus and have for the most part been used to determine the effect on parent's decision to disclose to the child. In this body of research, disclosure to the child is more likely if there has been disclosure to other acquaintances, close friends, and family (Peters et al. 2005; Rosholm et al. 2010). This chapter broadens the scope of research on conception disclosure to bring focus to a larger group including members of parent's familial and social networks. In this chapter, I also explore conception disclosure among individuals who use a variety of medicalized fertility treatment techniques.

The research questions guiding this chapter which are associated with my second research objective are as follows: *1) What are the underlying dimensions of disclosure attitudes about assisted conception? 2) Are there differences in disclosure attitude or behavior based on*

sexual identity? 3) What factors predict conception disclosure to the child? I quantitatively examine these questions based on a set of survey questions pertaining to respondents' attitude towards disclosure. I further examine differences based on sexual identity. With respect to conception disclosure behavior, I explore disclosure practices to individuals and several groups: work colleagues, child's school/nursery, social groups, acquaintances, close friends, family, family doctor, and offspring.

In this chapter, I first demonstrate that ART users' attitude toward disclosure has two underlying dimensions: one pertaining to non-disclosure and the other to disclosure. With respect to conception disclosure to children, family, professional and friendship network, I use the Communication Privacy Management framework to make the claim that parents who use ART manage information about their mode of conception through selective disclosure. I further argue that disclosure is instrumental in bringing visibility to individuals who otherwise do not neatly fit into the normative expectations about reproduction. Being in an openly gay or lesbian relationship potentially draws attention to how such couples would have created their family. In this chapter, I make the argument that this visibility is the reason sexual minority women are more open with other individuals about their conception. Sexual minority individuals' intentions or practices of disclosure reflect a desire for visibility and an intentionality in destabilizing notions of normality. Heterosexual women, who are otherwise apart of the dominant culture, on the other hand engage in selective disclosure out of fear of reproach and to preserve their status. Using a symbolic interactionism framework, I argue that people make sense of themselves as infertile or as users of ART based on societal views and make decisions about disclosure either to conform or to counter widely accepted sentiments.

II. RESULTS

ATTITUDE TOWARDS DISCLOSURE

A total of 18 items were included on the survey to measure attitudes towards disclosure. These items were developed for the purposes of this dissertation project based on major findings presented across the breadth of quantitative and qualitative studies on disclosure. The response to these items were measured on a five-point Likert scale from strongly disagree (1) to strongly agree (5). A list of these 18 items, along with mean values are presented in Table 5.1. On average, respondents were more inclined to agree with statements that were positively worded towards disclosure. These include: right-to-know; informing health-care professionals; having a support network; protecting the child from accidental discovery; and to demonstrate that the child is wanted. In contrast, respondents disagreed, on average, with statements that were negatively worded or leaning towards non-disclosure. These items include: avoidance of shame and stigma; poor treatment from family members; identity disruption; stigma; and impact on quality of parent-child relationship.

TABLE 5.1: ATTITUDE TOWARDS DISCLOSURE ITEMS

.	MEAN
1. Children have a right to know how they were conceived	3.97
2. Health-care professionals should be informed of patients' conception history	3.64
3. Disclosure is more difficult when there is a donor involved	3.60
4. Non-disclosure is the best way to avoid shame and stigma	1.92
5. One will know when the time is right to disclose	3.56
6. Families treat children poorly when they know the child was not conceived naturally	1.62
7. Disclosure threatens children's sense of identity	1.70
8. Disclosure leads to stigmatization	1.87
9. Having a support network makes disclosure less painful	3.96
10. Disclosure is the best way to protect the child from accidental discovery	4.01
11. Non-disclosure is the best way to protect the child	1.57
12. People are generally judgmental towards individuals who use medical assistance to conceive	2.60
13. The use of reproductive technology is a private matter	3.80
14. Parents should wait for the child to ask	2.18
15. Disclosure will negatively impact the parent-child relationship	1.50
16. Parents and children are 'co-owners' of their conception story	3.72
17. Health practitioners should be required to provide resources to assist with disclosure	3.09
18. Disclosure is a way to demonstrate to the child how much they are wanted	3.79

I used a Principal Component Analysis (PCA) to reduce these items to the smallest number of variables that explains the largest amount of variance and also to identify what construct(s) might exist in the data. At first, I used an oblique rotation, assuming that any existing factors or underlying constructs were likely to be correlated. The correlation statistics associated with the oblique rotation produced a value of .078 suggesting that the association between the components was weak (See Appendix E for additional tables). Subsequently, I conducted a Varimax rotation, which is reported later in the chapter results section (Table 5.5).

In these analyses the basic assumptions of factor analysis were met. For example, scholars recommend that there be at least 5 participants per variable (Gorsuch 1983). In this chapter, I entered 18 items into the analysis and the total sample size is 114. This exceeds the basic assumption of a 5:1 participant to variable ratio. I used the Kaiser-Meyer-Olkin (KMO) test

and the Bartlett's test to determine suitability for the data. As shown in Table 5.2, both statistics demonstrate that the data is suitable for a factor analysis with a KMO statistic of .70.[10] The Bartlett's test is also significant at the .001 level and indicates that the data is acceptable for a factor analysis.

TABLE 5.2: TEST OF ASSUMPTION FOR PCA

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.	.704
Bartlett's Test of Sphericity Approx. Chi-Square	450.537***

***p<.001, df =153

I used an eigenvalue of one or more as the criteria to determine the number of components to be extracted, consistent with the Kaiser criterion. Table 5.3 indicates that six components were extracted based on the aforementioned criteria. The six components included, have explained variance in at least one variable. All together, the six components explained approximately 63% of the total variance.

[10] The standard for the KMO statistics suggest that a value of .70 is considered average or normal.

TABLE 5.3: TOTAL VARIANCE EXPLAINED

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.641	20.227	20.227	3.641	20.227	20.227	2.441	13.564	13.564
2	2.699	14.995	35.222	2.699	14.995	35.222	2.104	11.691	25.255
3	1.498	8.302	43.424	1.494	8.302	43.524	1.970	10.943	36.197
4	1.342	7.458	50.982	1.342	7.458	50.982	1.890	10.499	46.696
5	1.113	6.182	57.164	1.113	6.182	57.164	1.556	8.646	55.342
6	1.036	5.756	62.919	1.036	5.756	62.919	1.364	7.578	62.919
7	.968	5.378	68.297						
8	.746	4.142	72.439						
9	.730	4.054	76.493						
10	.687	3.818	80.310						
11	.600	3.331	83.641						
12	.577	3.207	86.848						
13	.526	2.923	89.772						
14	.487	2.703	92.475						
15	.441	2.452	94.927						
16	.344	1.911	96.837						
17	.324	1.800	98.638						
18	.245	1.362	100.000						

Based on the Scree plot in Figure 5.1, there are two clear components at the point where the curve begins to flatten. Research methods text advise that the factors to be retained are those before the section of the curve at which point begin the eigenvalues level off (Bryman & Cramer 2001). A Monte Carlo Parallel Analysis also confirms the existence of two components since the eigenvalues obtained for the first two are higher than those generated for the first two components (see Appendix F).

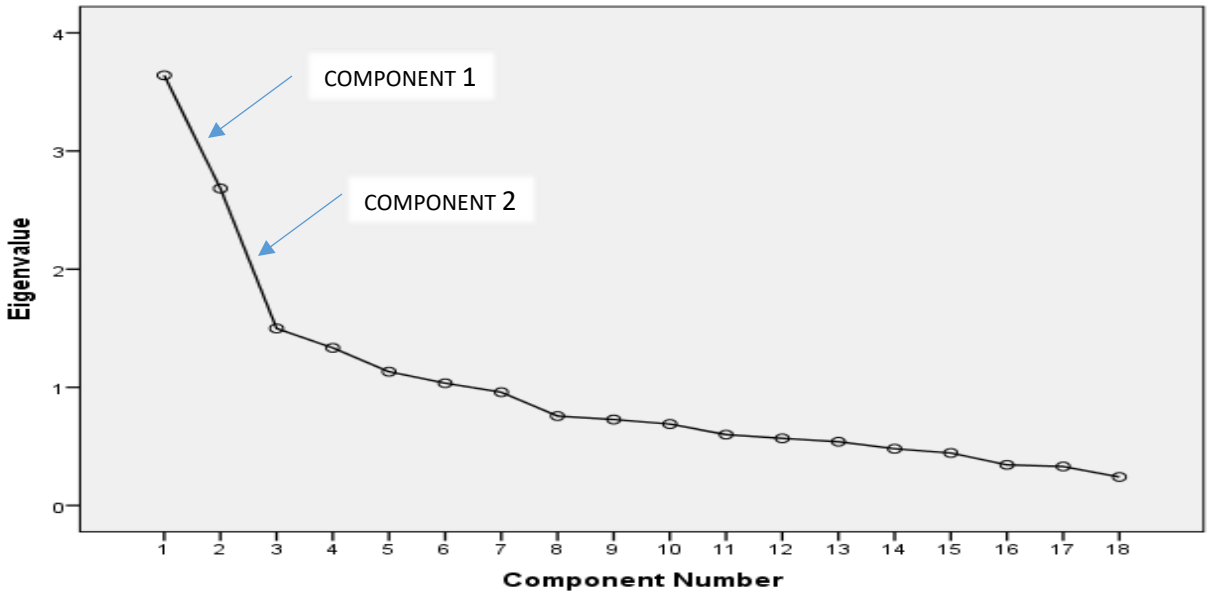


Figure 5.1: PCA Scree Plot

Following an examination of the total variance explained results (Table 5.3), the scree plot (Figure 5.1) and the Monte Carlo Parallel Analysis, the analysis was repeated to fix the number of components to two. Table 5.4 displays the total variance explained by the two components identified using a Principal Component Analysis with a Varimax rotation. Both components extracted explained approximately 35% of the total variance.

TABLE 5.4: TOTAL VARIANCE EXPLAINED

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.641	20.227	20.227	3.641	20.227	20.227	3.304	18.357	18.357
2	2.699	14.995	35.222	2.699	14.995	35.222	3.036	16.865	35.222
3	1.494	8.302	43.524						
4	1.342	7.458	50.982						
5	1.113	6.182	57.164						
6	1.036	5.756	62.919						
7	.968	5.378	68.297						
8	.746	4.142	72.439						
9	.730	4.054	76.493						
10	.687	3.818	80.310						
11	.600	3.331	83.641						
12	.577	3.207	86.848						
13	.526	2.923	89.772						
14	.487	2.703	92.475						
15	.441	2.452	94.927						
16	.344	1.911	96.837						
17	.324	1.800	98.638						
18	.245	1.362	100.000						

Extraction Method: Principal Component Analysis.

TABLE 5.5: ROTATED COMPONENT MATRIX

	Component 1	Component 2
Disclosure leads to stigmatization	.783	
Disclosure threatens children's sense of identity	.752	
Disclosure will negatively impact the parent-child relationship	.584	
Disclosure is more difficult when there is a donor involved	.562	
Non-disclosure is the best way to avoid shame and stigma	.526	-.427
People are generally judgmental towards individuals who use medical assistance to conceive	.512	
Families treat children poorly when they know the child was not conceived naturally	.416	
The use of reproductive technology is a private matter	.347	
Disclosure is the best way to protect the child from accidental discovery		.680
Children have a right to know how they were conceived	-.332	.610
Disclosure is a way to demonstrate to the child how much they are wanted		.594
Having a support network makes disclosure less painful		.563
Parents and children are 'co-owners' of their conception story		.562
Health practitioners should be required to provide resources to assist with disclosure	.388	.517
Non-disclosure is the best way to protect the child	.343	-.507
Parents should wait for the child to ask		-.454
Health-care professionals should be informed of patient's conception history		.333
One will know when the time is right to disclose	-	-

The objective of this analysis is to develop distinct measurement scales and so any item that loaded on more than one component was excluded. Additionally, items were selected if they had a loading of .3 or greater which suggest that there was at least a moderate correlation. Based on the two factor rotated component matrix in Table 5.5, the factors that singularly loaded highest on component one were: Disclosure leads to stigmatization; Disclosure threatens children's sense of identity; Disclosure will negatively impact the parent-child relationship; Disclosure is more difficult when there is a donor involved; People are generally judgmental towards individuals who use medical assistance to conceive; Families treat children poorly when they know the child was not conceived naturally; and The use of reproductive technology is a private matter. These factors all had positive loadings on component one. I examine the items for each of the respective components using a reliability analysis (Appendix G). The first component comprises a set of seven items, which I describe as fear suppressed disclosure. The seven items included in component one are shown in Figure 5.2 and result in the highest possible Cronbach's

alpha value of .708. The items represent concerns or anxieties about the ramification of disclosure and lean more towards non-disclosure.

Figure 5.2: Fear Motivated Non-Disclosure

Consequences include stigma; judgment; poor treatment; impact on the parent and child relationship; loss of identity; related difficulty when a donor is involved; and a need or desire to preserve privacy. The items were combined to create a scale for further analysis.

On component two, the factors that positively and singularly loaded highest were: Disclosure is the best way to protect the child from accidental discovery; Disclosure is a way to demonstrate to the child how much they are wanted; Having a support network makes disclosure less painful; Parents and children are co-owners of their conception story; and Health-care professionals should be informed of patient's conception history. Another factor, parents should wait for the child to ask, had a negative loading on component two. The initial six items

identified from the PCA were reduced to the four that produced the highest possible Cronbach's alpha value of .622 (shown in figure 5.3).

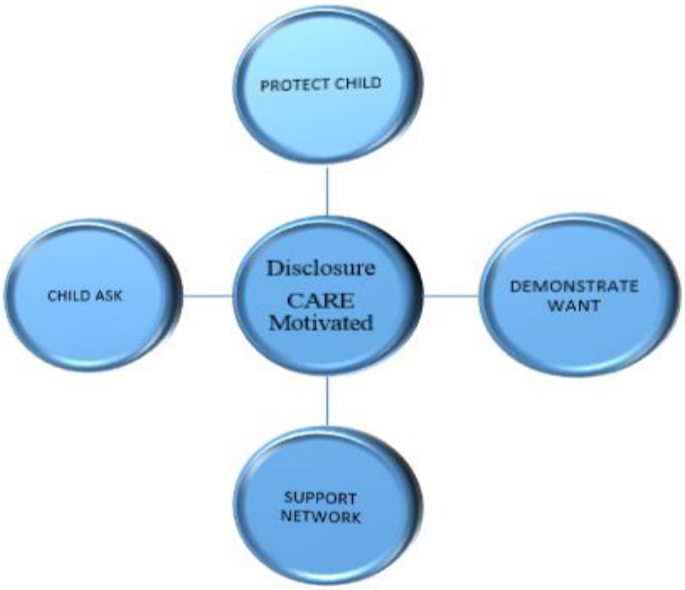


Figure 5.3: Care Motivated Disclosure

These four items are more positive and support disclosure as motivated by care for the wellbeing of the child. These items were combined to create a scale variable for further analysis.

VALIDATION OF THE SCALES

A basic binary logistic regression was carried out to further validate the fear motivated non-disclosure and the care motivated disclosure scales (N=103). I used one survey question as the dependent variable: *Have you disclosed to your child(ren) about how they were conceived?* with response options "yes" and "no"; option no was used as the reference category. To examine the performance of the scales, I hypothesized that individuals who have lower scores on the fear motivated non-disclosure scale and those who have higher scores on the care motivated disclosure scale are more likely to disclose conception information to their children.

For the most part, the results are consistent with the aforementioned hypotheses. The results from the simple binary logistic regression (Table 5.6) shows that the fear factor scale does

not significantly predict whether a parent discloses to their child at the 95% confidence level. Although, not a significant predictor, individuals who had higher score on the fear factor non-disclosure scale had a higher likelihood to not disclose conception information to their child.

TABLE 5.6: BINARY LOGISTIC REGRESSION PREDICTING CONCEPTION DISCLOSURE TO CHILDREN BASED ON ATTITUDES TOWARDS DISCLOSURE SCALE

	FEAR MOTIVATED NON-DISCLOSURE		
VARIABLE	B	SE	ODDS RATIO
FEAR FACTOR SCALE	-0.90†	0.054	0.914
CONSTANT	1.120	0.905	3.063

† Significant at the 90% Confidence Level (P=0.093)

As shown in Table 5.7, the care factor scale is a significant predictor of conception disclosure to children ($p<.05$). The odds of conception disclosure to the child was higher among those parents who scored better on the care factor scale (OR= 1.224). Although these results support my hypothesized relationships between these variables, in part, further cross-validation based on different samples would add more credibility to the development of these scales and construct.

TABLE 5.7: BINARY LOGISTIC REGRESSION PREDICTING CONCEPTION DISCLOSURE TO CHILDREN BASED ON ATTITUDES TOWARDS DISCLOSURE SCALE

	CARE MOTIVATED DISCLOSURE		
VARIABLE	B	SE	ODDS RATIO
CARE FACTOR SCALE	0.203*	0.085	1.224
CONSTANT	-3.554	1.355	0.029

DIFFERENCE BASED ON SEXUAL IDENTITY

I used a t-test to assess differences in the two scales based on sexual identity. On the fear motivated non-disclosure scale a combined 7-item scale, the maximum score possible is 35 and the minimum is 7. Results indicate that 80 heterosexual identified participants had a mean score of 17.29 points on this factor. As shown in Table 5.6, the 24 LGBQ identified women had a

mean score of 14.71. The Levene's test for Equality of Variances indicates that the variances for heterosexual and LGBQ identified individuals did not significantly differ from each other. Based on the t-test results, there is a statistically significant difference in the mean score on the fear motivated non-disclosure scale between heterosexual and LGBQ identified individuals ($p<.01$). Based on the means scores, the heterosexual group's attitude towards disclosure was motivated more by a fear of various possible repercussions relative to their LGBQ counterparts.

Based on the mean scores obtained for the two groups it appears that both groups have low to moderate fear motivated non-disclosure. More specifically, the LGBQ group had a low attitude towards non-disclosure out of fear of the consequences while the heterosexual identified group had a more moderate level of fear.

TABLE 5.8: BIVARIATE OF SEXUAL IDENTITY

	SEXUAL IDENTITY			
	HETEROSEXUAL	LGBQ	*t*	*df*
FEAR FACTOR	17.29 (3.93)	14.71 (3.26)	2.922**	102
CARE FACTOR	15.44 (2.55)	16.04 (2.69)	-0.976	102

Note. ** = $p < .01$. Standard Deviations appear in parentheses below means

On the care motivated disclosure scale, heterosexual identified participants had a mean of 15.44 and LGBQ identified women had a mean of 16.04 (Table 5.8). The Levene's test for Equality of Variances indicates that the variances for heterosexual and LGBQ identified individuals do not differ significantly from each other. The t-test results demonstrate that the mean score on the care motivated disclosure scale does not differ significantly ($p>.05$).

DISCLOSURE BEHAVIOR

When it comes to disclosing to **work colleagues,** participants who identified as heterosexual were more likely to disclose to a few/some while those who identified as LGBQ were equally likely to disclose to few/some as well as most/all. Approximately 72% of

heterosexually identified participants have disclosed to a few or some work colleagues, 12% had disclosed to most/all and 16% had disclosed to none of their work colleagues. For LGBQ 46% had disclosed to few/some work colleagues and an equal proportion to most/all (Table 5.9). Only 8% of sexual minority women declared that they had disclosed to none of their work colleagues. The relationship between sexual identity and disclosure to work colleagues was statistically significant (p<.01).

TABLE 5.9: BIVARIATE OF SEXUAL IDENTITY & DISCLOSURE TO WORK COLLEAGUES

	SEXUAL IDENTITY				
	HETEROSEXUAL	LGBQ	X^2	*df*	*N*
NONE	16.0	8.3	13.024**†	2	105
FEW-SOME	71.6	45.8			
MOST-ALL	12.3	45.8			

Note. **p<.01, *df* =2. † Results must be cautiously interpreted, expected count less than 5 greater than 20%

Disclosure to **children's school or nursery** is less popular among participants in the survey, especially among heterosexual identified participants. As shown in Table 5.10, only 7% of heterosexually identified women have fully disclosed to the children's school or nursery and another 32% claimed to have disclosed to few/some. Six of every 10 heterosexual identified participant have not disclosed to their children's school or nursery. Among the LGBQ identified individuals approximately 38% have disclosed to few or some and the same proportion disclosing to most or all. Approximately 24% of the LGBQ identified women had not disclosed to any of the personnel at the childcare or educational institution in which their child is enrolled. The relationship between sexual identity and disclosure to the child's school or nursery is statistically significant (p<.001).

TABLE 5.10: BIVARIATE OF SEXUAL IDENTITY & DISCLOSURE TO CHILDREN'S SCHOOL/NURSERY

	SEXUAL IDENTITY				
	HETEROSEXUAL	LGBQ	X^2	*df*	*N*
NONE	60.6	23.8	15.412***	2	92
FEW-SOME	32.4	38.1			
MOST-ALL	7.0	38.1			

Note. ***p <.001

There is also a statistically significant relationship between sexual identity and disclosure to **social groups or communities** (p<.01). Slightly more than one half of heterosexuals (55%) indicated that they had disclosed to few/some members of their social groups and another 10% had disclosed to most/all. Slightly more than one third (35%) of heterosexual identified individuals had not disclosed to any members of their social organizations. LGBQ identified individuals were also more likely to disclose to few/some (57%) community members. About 38% indicated that they had disclosed to most/all the members of their social groups or community. Non-disclosure to social groups was least likely among the LGBQ group; only 5% said they had disclosed to none of those persons (Table 5.11).

TABLE 5.11: BIVARIATE OF SEXUAL IDENTITY & DISCLOSURE TO SOCIAL GROUPS/COMMUNITY

	SEXUAL IDENTITY				
	HETEROSEXUAL	LGBQ	X^2	*df*	*N*
NONE	34.6	4.8	13.160**	2	99
FEW-SOME	55.1	57.1			
MOST-ALL	10.3	38.1			

Note. **p <.01

Disclosure behavior, when it comes to **casual friends and acquaintances,** follows a similar pattern as those for social groups and communities. Approximately six of every 10 heterosexual identified participant had disclosed to few/some casual friends and acquaintances. Another 22% had disclosed to most or all casual friends or acquaintances. A smaller but notable 17% of heterosexual identified women had not disclosed to any of their casual friends and

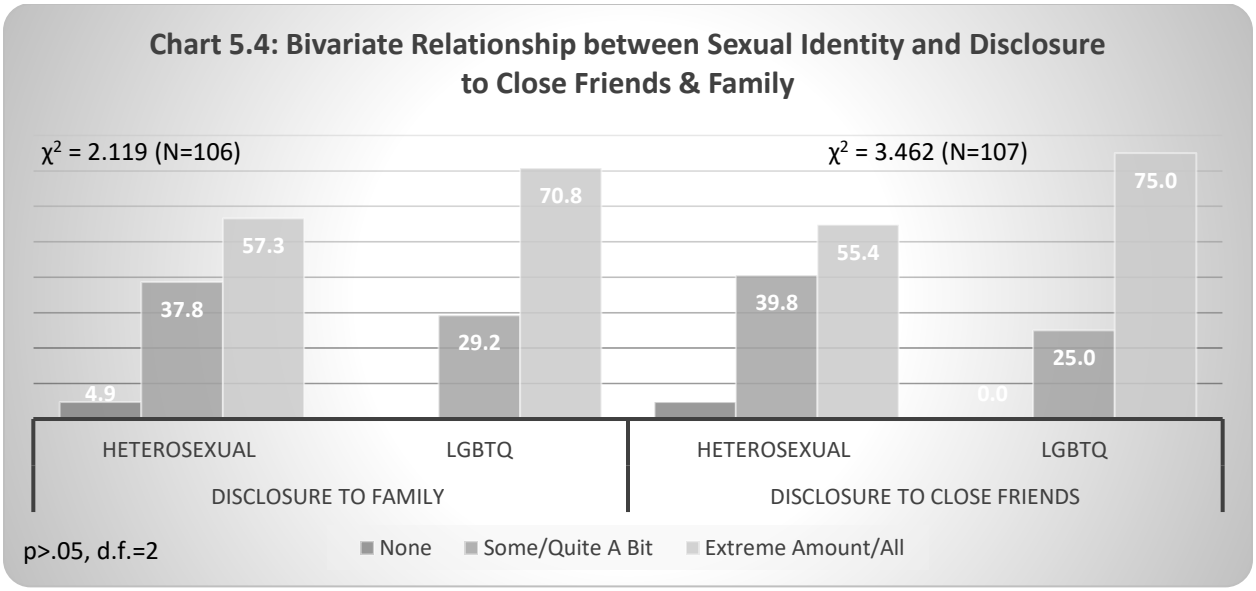
acquaintances. Among the LGBQ identified participants, 58% had disclosed to few or some casual friends and another 42% had disclosed their conception story to most or all of their friends and acquaintances. Overall, sexual minority women had disclosed to at least a few of their casual friends and acquaintances. As shown in Table 5.12, the relationship between sexual identity and disclosure to casual friends and acquaintances is statistically significant ($p<.05$).

TABLE 5.12: BIVARIATE OF SEXUAL IDENTITY & DISCLOSURE TO CASUAL FRIENDS/ACQUAINTANCES

	SEXUAL IDENTITY				
	HETEROSEXUAL	LGBQ	X^2	*df*	*N*
NONE	16.9	0.0	6.918*	2	107
FEW-SOME	61.4	58.3			
MOST-ALL	21.7	41.7			

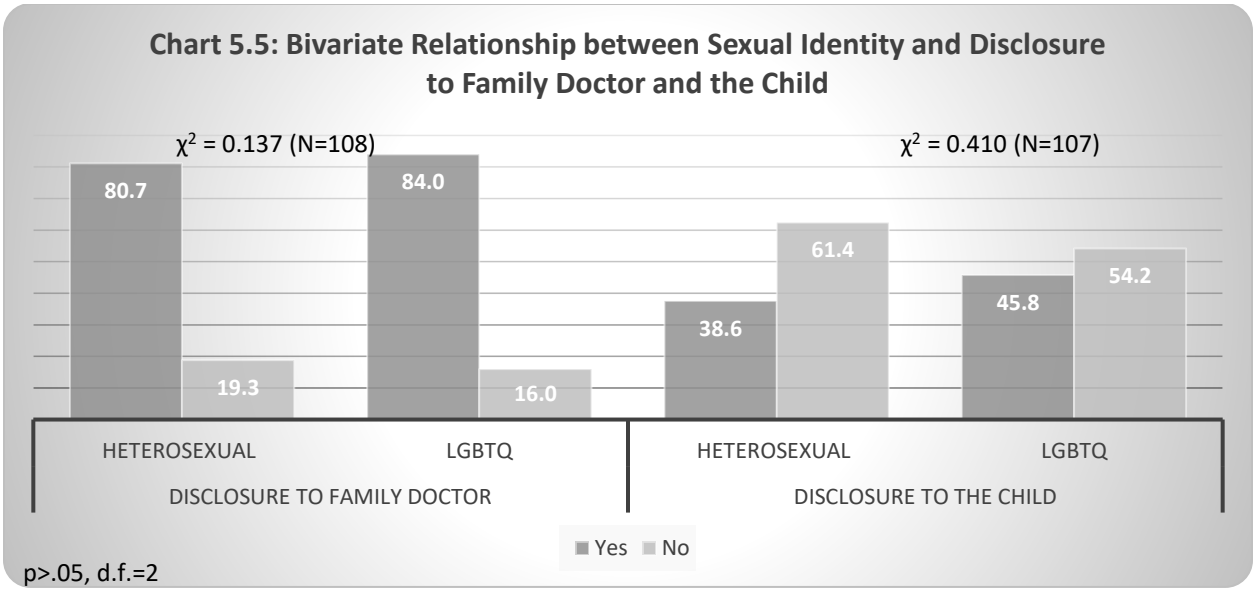
Note. *p <.05

Based on the survey data, there is no statistically significant relationship in disclosure behavior when it comes to more personal networks based on sexual identity. As shown in chart 5.4, both groups were more likely to disclose to family members and close friends. Consistently however, LGBQ identified individuals were more likely to disclose to their family and friends. Almost three fourths of the LGBQ participants had already disclosed to close friends and family respectively, compared to just about a half of those participants who identified as heterosexual.



† Results must be cautiously interpreted, expected count less than 5 greater than 20%

Sexual identity did not significantly influence disclosure to family doctor. As shown in Chart 5.5, disclosure to a family doctor appears to be equally important among heterosexual and LGBQ identified individuals. Four of every five participants within both groups had already disclosed to their family doctor. The patterns are slightly less striking when it comes to disclosure to children. Although not statistically significant, LGBQ identified participants were slightly more likely to have disclosed to their child; 46% compared to 39% of those who identified as heterosexual. In a study of donor conceived offspring, Lalos et al. (2007) found that children of lesbian and single parent families were more likely to have been told (at a younger age) about their conception when compared to children from heterosexual families.



† Results for family doctor must be cautiously interpreted, expected count less than 5 greater than 20%

I further conducted a logistic regression analysis to examine the factors that predict parents' decision to disclose about conception to the child. The dependent variable is based on the survey question, *"Have you disclosed to your child(ren) about how they were conceived?"* with response options "yes" and "no." I used the response option "no" as the reference category. Select sociodemographic and reproductive history factors were entered into a single logistic regression model as independent variables to predict the probability of conception disclosure to the child. Age of the mother and number of children conceived with the use of ART were interval/ratio variables while all other variables were dichotomously coded with reference categories displayed in parentheses (Table 5.13).

The independent variables were purposefully selected based on a review of previous studies. Sexuality is a critical variable in my analysis and previous studies have found differential treatment and experience based on sexual identity (Peel 2009; Rondahl et al. 2009). Scholars have also explored the effect of the age of the parent on disclosure with mixed findings (Hershberger et al. 2007; Peters et al. 2005). Race, marital status, education, and employment

status were included in the logistic model because they are known predictors of fertility treatment access (Bitler & Schmidt 2006; Chambers et al. 2013; Kessler et al. 2013). The presence of other siblings in the household on conception disclosure is among variables explored and discussed in previous research (Peters et al. 2005). Studies have also found differences in disclosure decisions between parents who used donor gametes and those who did not, which is also related to parents' experience of infertility (MacCallum & Keeley 2012; Rosholm et al. 2010).

TABLE 5.13: LOGISTIC REGRESSION PREDICTING CONCEPTION DISCLOSURE TO THE CHILD

VARIABLES	*B*	SE	ODDS RATIO
SEXUALITY (LGBQ)	0.350	0.861	1.419
WHITE (NON-WHITE)	0.480	0.890	1.503
MARRIED (UNMARRIED)	-0.999	0.706	0.368
AGE	0.066†	0.035	1.068
COLLEGE EDUCATED (HIGH SCH/TECHNICAL)	-0.281	1.315	0.755
EMPLOYED (UNEMPLOYED)	0.102	0.776	1.107
#ART CONCEIVED CHILDREN	0.032	0.261	1.032
DONOR EMBRYO (NO)	2.033†	1.178	7.639
DONOR SPERM (NO)	1.320	0.926	3.743
INFERTILITY (NO)	-0.327	0.558	0.721
DIAGNOSED INFERTILITY (NO)	0.451	0.472	1.571

† Significant at the 90% Confidence Level

The results of the logistic analysis showed that none of the variables included are significant predictors of conception disclosure at the .05 level of significance.[11] I would like to note, however, that age of the mother and the use of donor embryo were significant predictors at the 90% level of confidence. The odds of conception disclosure to the child was higher for older mothers (*B*=0.066, P=0.63) and parents were more likely to disclose about conception if they had

[11] As discussed in Chapter 3, the sample is small and therefore limits multivariate analysis. Additionally, there is significant skewness on some variables. Sample is overwhelmingly white, college educated, and a significant proportion identifies as heterosexual.

used donor embryo (*B*=2.033, P=0.084). Clear differences based on sexual identity do not overwhelmingly feature in my data; however, in subsequent chapters I discuss nuanced experiences among sexual minority women. I also discuss some qualitative explanations provided by parents to support conception disclosure that will help to elucidate why the factors included in the logistic model are non-significant predictors. Irrespective of socio-demographic background, experience of infertility, and use of donor, parents identify factors that are all-encompassing and substantively important factors for disclosure. For example, the use of a donor and the experience of infertility are considered significant aspects of the child's medical history and factors into disclosure decisions as a larger experience and personal story.

III. DISCUSSION

Reasons for non-disclosure are consistent with those found in previous research (Readings et al. 2011; Rosholm et al. 2010; Shehab et al. 2008). Privacy concerns, identity disruption, harmful effect on the parent-child relationship, stigmatization, feeling judged, donor involvement, and poor treatment by extended family members have consistently been among the complex issues driving non-disclosure. My data shows that these justifications are not entirely independent of each other, but that the underlying motivation is a general sense of fear regarding social consequences. Additionally, the data suggests that attitudes toward disclosure are based on a care and support model that includes the child and members of their network. A desire for the child to appreciate how much they were loved through an understanding of their determination to bring them into the world was among the reasons parents disclosed. Similar to findings from researchers such as Hershberger et al. 2007, the desire to maintain a culture of honesty and trust within the family and to protect the child from accidental exposure also motivate parents' attitude towards sharing conception information with their offspring. The items used to develop both the fear motivated non-disclosure and care motivated disclosure scales are consistent with

the factors identified in previous research as reasons for disclosure and non-disclosure. This provides a considerable amount of face validity for the scales I have developed in this chapter.

The overall results suggest that heterosexual identified individuals, compared to those in the sexual minority group, are significantly less inclined to disclose out of fear of the possible social consequences. Why might such differences exist? Supplemental chi-square analyses between sexual identity and each item on the fear motivated non-disclosure scale suggests that the key difference rest on donor involvement (Appendix H). Heterosexual identified individuals were more likely to agree that disclosure is more difficult when there is a donor involved. Studies suggest that the lack of genetic relations to one or both parents significantly influences non-disclosure (e.g., Rosholm et al. 2010). Research suggest that among persons who use donor gametes, non-disclosure was motivated by a lack of genetic ties and the desire to protect the non-biological parent (MacCallum & Keeley 2012).

Studies have found that women who experience infertility construct it as a negative identity, internalize this as a failure of their bodily processes to function as normal, and perceive themselves as inadequate (Williams 1997). The tendency to frame infertility as a deficit or in Goffman's (1963) terms, a *discredited status*, is based on perceived and internalized social norms about womanhood as inseparable from motherhood. In the conception disclosure literature, studies suggest that women who experience infertility, account for this discredited status in their disclosure decisions (Hershberger et al. 2007; Mohanty et al. 2014). Ultimately, women see their conception history as inextricably linked to their experience of infertility. In a sample of heterosexual women, Blyth et al. (2010) found that participants were more likely to disclose to friends and family about their use of donor insemination if they had prior knowledge of the couple's fertility challenges. Participants in the same study, engaged in selective

disclosure, when they perceived that persons had negative attitudes towards assisted conception. Based on my sample, approximately 83% of heterosexual identified and 56% of LGBQ identified women met the medical definition of infertility (Appendix G). Although, only 40% of the heterosexual group and 24% of the LGBQ identified group received a confirmatory medical diagnosis. Given that heterosexual identified women are more likely to meet the definition of and being diagnosed as having infertility issues, it stands to reason, that for heterosexual women in my sample, disclosure about the use of ART is ostensibly associated with their experience and disclosure of their experience of infertility.

Parenting for lesbian and gay persons has historically been a politically charged one around recognition, visibility, rights, equality, and access. For LGBQ individuals their sexual identity exposes them to public scrutiny. The body of scholarship on parenting among gay parents, in particular, speak to such social confrontations about how they became parents (Gamson 2015). The lack of a visible, opposite-sex partner raises questions about relatedness of children in the care of lesbian and gay adults. For those engaged in same-sex partnerships, there is already a public curiosity about how they became parents, which places pressure on them to *come-out* about their conception decisions and experience(s). For many lesbian, gay or queer persons, becoming a parent *outed* them; sometimes deliberately in their demands for recognition and sometimes unintentionally in response to curious observers. According to Luce (2010), the presence of children makes it difficult to displace queerness, as persons are often called upon to answer questions about who the child belongs to (p.49). Therefore, bringing visibility to a group of individuals who have previously been excluded from most pathways to (biological) parenthood is of paramount importance to LGBQ persons. So, while disclosure about the use of ART for heterosexual women is potentially suppressed by their infertility status, LGBQ

identified individuals are empowered by their experience within a long historical and contemporary scrimmage over access to parenthood, as part and parcel of a politics of sexuality, reproduction, and visibility.

IV. CONCLUSION

In the case of medically assisted reproduction, the use of scientific intervention to conceive is still a controversial decision in the twenty-first century. In March 2015, the renowned fashion designers, Dolce & Gabbana (D&G), caused a frenzy on social media. During an interview, the designers made a comment that referred to children conceived with the use of reproductive technology as "synthetic children." Whether this is a widely-held sentiment or not is yet to be determined; however, there were many persons who came out in the designer's defense. Understanding how people make sense of ART and how users position themselves vis-à-vis these epithets of unnatural or synthetic is of sociological significance. Additionally, knowing more about how people define, understand, and choose to build their families as well as strategically manage their conception information (e.g., who they decide to share with and how they shape such disclosure), must be understood within shifting and highly politicized sociocultural contexts.

Individuals in this study engaged in a collective sharing of information. Based on the communication privacy management theory persons made decisions about revealing or concealing information and created boundaries to manage the information (Petronio & Caughlin 2006; Rauscher & Fine 2012). Parents decision to approach disclosure differently across personal and professional networks is demonstrative of their attempts to build and maintain information boundaries. For instance, heterosexually identified individuals were less invested in openly disclosing to the child(ren)'s school or nursery and also to social groups compared to their LGBQ identified counterparts.

My data shows that heterosexual individuals are more likely to engage in a process of selective disclosure. I argue that this is due primarily to the inseparability of the children's conception story to the parents' own history of infertility. This is especially true regarding the use of donor gametes and the overall social consequences if a person's discredited status as infertile/ART user is exposed. Non-disclosure allows heterosexual identified individuals in particular to pass as fertile-normal parents, the traditional nuclear family with mom, pop and the biological offspring. Non-disclosure about fertility treatment and mode of conception is therefore a privilege most accessible to heterosexually identified women. Selective disclosure is more challenging for sexual minority persons who could only achieve the appearance of normal fertile parent status if they remained closeted. Research further suggests that lesbian women felt that having children legitimized their relationship and additionally produced a queer visibility (Luce 2010). The management of conception information among ART users has to do with the perceived stigma associated with infertility and sexuality. A heterosexual identity and the related experience of infertility limits disclosure, and a sexual minority identity inspires disclosure to demand visibility and recognition.

On a methodological note, our understanding of conception disclosure thus far is based on a mix of qualitative and quantitative research. Qualitative research approaches use open-ended and probing questions to explore parental concerns as well as thought processes and strategies with respect to disclosure (e.g., Hershberger et al. 2007). Quantitative studies, on the other hand, have predominantly employed the use of polar questions (yes or no) to measure actual disclosure; sometimes including questions on intent and always with an emphasis on the child (Gottlieb et al. 2000; Landau & Weissenber et al. 2010; Lycett et al. 2005; Macallum & Golombok et al. 2007). Given the complexity of disclosure, I demonstrate that the development

of a *non/disclosure scale* which uses more quantifiable questions, provides an alternative to measuring disclosure attitudes and practices in contrast to more static yes or no responses. Scholars have suggested that disclosure and non-disclosure are not opposites of the same coin and that this oppositional binary approach fails to recognize its complexity. They further suggest that disclosure is more than just privacy on the one hand and full disclosure on the other, but in many instances, is an effort to manage the tension between the two (Petronio & Caughlin 2006). Consequently, any research on disclosure should include all potential information shareholders and should recognize disclosure as a continuum. Survey questions that allow for quantification similar to those utilized in this study provides more details or rather provides a better understanding of how conception disclosure is approached.

My findings contribute to our understanding of disclosure, and give primacy to research on disclosure across a larger social network. Overall, the data supports my research hypotheses that LGBQ participants are more likely than their heterosexual identified counterparts to disclose across their private and social networks about their conception (hi)stories. The difference on the fear non-disclosure scale is statistically significant and demonstrates that non-disclosure among heterosexual identified individuals' is inspired more by fear than their LGBQ counterparts. Importantly, sexual minority women were more open compared to their heterosexual identified counterparts. An inclination towards disclosure appears to be one that is inspired by care that extends from parent to child, but also includes a wider support system. Although LGBQ identified participants were slightly more likely to support disclosure, the difference between the two groups is not statistically significant.

Disclosure about conception through ART is an intricate, complicated, and convoluted matter. As discussed in Chapter 2 and reiterated in part within this chapter, disclosure is an

amalgamation of events, experience(s), and circumstances including: parents' own struggles with infertility; the presence of other siblings; the child's genetic origins; potential psychosocial effects on the child; age of the parents, particularly mother; and type of medical assistance used. My data demonstrates that sexuality is also a critical variable in the analysis of conception information management among ART users. The variation in the number of persons with whom respondents had shared their conception information, even within groups, further hints at the complexity of the disclosure process as one involving varying degrees of privacy and/or disclosure. Fear and care are not absolutes, disclosure and non-disclosure are not opposites, but rather extremes along a continuum. Respondents in the sample did not completely disclose to any group of individuals therefore indicating that disclosure is not tantamount to full disclosure. Conception information management is therefore about resolving the tension between secrecy and open communication, between fear and care, sometimes choosing the extreme and other times situating oneself somewhere along the spectrum.

Although my analysis broadens our understanding of disclosure attitudes and practices, there are a number of limitations. Firstly, disclosure is not a onetime event and so cross-sectional data does not allow for a comprehensive examination of disclosure decisions and behaviors. Secondly, age and other characteristics pertaining to the child and household were not included on the survey. Based on some timing variables including the age of the mother as well as some qualitative responses it appears that the age of the children varies for the individuals in the sample. Among those who have not yet disclosed, the age of the child is an important aspect of that decision. Discussed further in Chapter 7, several of the participants who intend to disclose reference an appropriate age at which they will embark on conception disclosure. This age varied

from one parent to the next – from as young as the child can understand to an age where they might also themselves be faced with fertility challenges.

The next two chapters will explore the importance of conception disclosure as well as disclosure behavior specifically pertaining to children in more detail. The analyses and discussion which follows are predominantly base on the examination of qualitative responses to the specific survey questions.

CHAPTER 6

IMPORTANCE OF CONCEPTION DISCLOSURE TO CHILDREN

I. INTRODUCTION

The importance of disclosing conception information has been recognized and ratified by law in several countries. In 2008 the United Kingdom revised its Human Fertilisation and Embryology Act 1990 as a show of support for parental disclosure. The revision requires that fertility clinics provide information to persons considering donor insemination as it pertains to: early disclosure to any child resulting from gametes from individuals who are not engaged in the parenting of the child and about appropriate methods of disclosure (Blyth et al.2010). Sweden, Austria, Switzerland, the Netherlands, Norway, Finland, and the Australian states of Victoria, New South Wales and Western Australia have all implemented policies in favor of donor conception information disclosure to children (Lycett et al.2005; Mac Dougall et al.2007; Victorian Assisted Reproductive Treatment Authority – VARTA 2014). In the United States, the Ethics Committee of the American Society for Reproductive Medicine advocates for disclosure in the best interest of the child (ASRM 2013). Although these policies are specifically geared towards donor conception disclosure, they should also inspire open dialogue about assisted reproduction disclosure in general, with or without the use of gamete donation.

Disclosure to donor conceived children has gained primacy in research on assisted conception. According to this research, there have been significant shifts in the recommendations about disclosure: moving away from secrecy to open disclosure and including a position that disclosure depends on other factors (Golombok 1997). Survey results from the Society of Reproductive Endocrinology found that 56% of its members supported disclosure to children conceived using artificial donor insemination while the other half were either neutral or not in

support (Leiblum & Hamkin 1992). Daniels (1997) suggests that the earlier push for secrecy emerged from the practice of doctor/patient privacy privileges and overall social attitudes towards donor insemination. In this contemporary moment, however, the right-to-know narrative and the-best-interest-of-the child discourse, framed within the context of the United Nations Convention on the Rights of the Child pervading legal discourse, suggests that disclosure is important for the overall health and positive development of the child (Ravenlingien & Pennings 2013; Ravitsky 2012). However, some parents dissent from the popular view on open disclosure and argue instead that it is unnecessary for children to know about their conception (Gottlieb et al. 2000).

This chapter examines views on the importance of disclosing conception information to children, from the point of view of the women who conceived with the use of assisted technologies. The research questions guiding this chapter related to my second research objective include: *1) Are there differences in the perceived importance of disclosing to offspring about their conception between heterosexual and sexual minority identified women? 2) What are the factors that inspire disclosure to offspring? 3) Do these factors differ on the basis of sexual identity?* I examine these questions using a combination of closed-ended and open-ended questions from my online survey. The survey questions asked respondents: "How important is it to share information with your child(ren) about their conception?" and "Please share more about why you think it is important, somewhat or not important?" Overall, I hypothesize that sexual minority individuals are likely to place more importance on disclosure to children and will rationalize this differently relative to their heterosexual identified counterparts.

In this chapter, I use a symbolic interactionism framework to interpret the importance of ART disclosure to normalize assisted conception and to destigmatize ART use and infertility.

This is in response to ideas about natural conception, traditional reproduction and normal family. Additionally, the positive frames of ART as cool and amazing are part and parcel of the efforts to disrupt and destabilized negative connotations about nonnormative childbearing techniques.

As previously stated in Chapters 3 and 4, the quotes highlighted in this chapter are verbatim and in most cases included in their entirety. This is done to preserve the authenticity of very concise, rich, and chock full survey comments.[12] For these reasons, some comments provide overlapping details and create connecting threads across the thematic areas that organize this chapter. These crosscutting details demonstrate the complexity of ART use and disclosure about it, which makes it difficult as a researcher to distill a single aspect of the participants' experience without distorting their stories. Consequently, themes discussed in this chapter are not mutually exclusive. To assist with readability, bold front is used to draw reader's attention to specific details in longer extracts.

II. RESULTS

IMPORTANCE OF DISCLOSURE TO CHILD(REN)

To understand patterns of disclosure regarding medically assisted conception to children, we must first understand the individual's point of view on the importance of disclosure in a general sense. Overall, approximately 45% of participants stated that it was very important to disclose to children, about 44% said it was somewhat important, and 11% stated that it was not at all important (N=108). For the purposes of this analysis, I examine participant's opinions based on their sexual identity, and demonstrate those results in Table 6.1. Both groups, heterosexual- and sexual minority-identified women, place some importance on disclosure to children about their conception. Two of every five heterosexual-identified participants indicated that disclosure

[12] Each quote provided represents a different survey participant.

to offspring was “very important.” Overall, heterosexual women were more likely to say it is “somewhat important” (47%). LGBQ identified participants were more likely to say that it is “very important” (60%). Almost one third of LGBQ identified women (32%) in the sample said disclosure to offspring was “somewhat important.”

TABLE 6.1: BIVARIATE OF SEXUAL IDENTITY & IMPORTANCE OF DISCLOSURE TO CHILDREN ABOUT CONCEPTION

	SEXUAL IDENTITY				
	HETEROSEXUAL	LGBQ	X^2	*df*	*N*
NOT IMPORTANT	12.0	8.0	2.810	2	108
SOMEWHAT IMPORTANT	47.0	32.0			
VERY IMPORTANT	41.0	60.0			

Note. p >.05

Although the relationship between sexual identity and the perceived importance of disclosing to children about their conception is not statistically significant (p>.05), the difference between heterosexual-identified participants and sexual minority-identified women within the “very important” response category is noticeable. These results beg the question - why are sexual minority-identified individuals slightly more likely than heterosexual-identified participants to think that disclosing to the child is of any importance? I examine responses to the open-ended comments to elucidate further explanations about the importance of disclosure.

There are five themes that I discuss in this chapter pertaining to the perceived importance of disclosure: 1) Affirmation of Love & Desire; 2) Honesty Permits Bonding, Secrecy Breeds Shame; 3) Their Conception Story; 4) Normalizing Medical Conception; and 5) Romanticizing the Science. The data suggest that a key difference emerges between heterosexual- and sexual minority-identified participant in their desire to have an open and honest relationship with the child. While there is a considerable amount of consensus among both groups about the implications of disclosure within the five thematic areas, ultimately I find that sexuality plays a

salient role in the parents' desire for openness. I argue that the importance of disclosure among sexual minority participants can be explained by queer reproduction and visibility - specifically the inevitability of donor insemination and in most cases, the absence of a male/father figure in the child's life.

PERCEIVED NON/IMPORTANCE

Survey participants were asked to further elucidate their thoughts on the importance of conception disclosure to their children. Participants who think that disclosure to the child is not important tend to reject any notion of difference between children conceived naturally and those conceived with ART, and as such thought disclosure was inconsequential. Among the specific justifications provided by participants who thought disclosure was unimportant in my survey were: conception through IUI (not IVF); the child is biologically related to both parents; and having discussion about how a child was conceived with the child is extraneous and atypical under any circumstance. These results are generally consistent with previous research discussed in Chapter 2, which found that conception disclosure differs based on the mode of conception. Most importantly, it varies on account of the child's biological relatedness to the parents (Readings et al. 2011; Rosholm et al. 2010) which tends to be one way to establish a difference between natural and ART conceived children.

Overwhelmingly, women in my sample view conception disclosure as either very important or somewhat important. Consistent with this viewpoint, the majority of the sample have already disclosed or intend to disclose to their children about their conception. The following analysis represents the perspectives of women who hold the view that disclosure is at least of some importance. Irrespective of their own practice of disclosure, participants' comments overwhelming implied that there were productive implications to conception disclosure.

AFFIRMATION OF LOVE & DESIRE

A number of participants described disclosure as a necessary part of establishing an affective connection with the child, especially through associating the mode of conception with their desire to have a child. One non-Hispanic white heterosexual individual stated, *"I want my child(ren) to know how much they were loved and wanted."* This notion of want reverberated throughout several participants' comments and featured most dominantly among heterosexual identified participants. A non-Hispanic white heterosexual contributor wrote, "*I just want him to know how much he was wanted.*" Another non-Hispanic white heterosexual participant stated, *"I wanted my son to know that he was a very "wanted" child."* For these individuals, disclosure about the child's conception was significant in positively affirming both their desire to have the child and love for the child. In a study of adolescent children, participants suggested that parental attitude is crucial to the process of disclosure and recommended that a "reassurance of parental love" was a necessary part of communicating donor assisted conception (Kirkman et al. 2007:2321).

Parents' demonstration of *wanted-ness* relied on explanations about the difficulty and painstaking process of becoming pregnant. One Hispanic heterosexual identified participant commented, *"They should know how much they were wanted and through what their parents went through because we wanted to have them so much."* Another Hispanic heterosexual identified participant stated, "*I have not thought about this thoroughly. but i want him to know how much I desired him and how far I was willing to go to be his mom."* And another non-Hispanic white heterosexual identified participant commented, "*I want them to know we had trouble, that there is assistance available… Also, I hope it will help them know how much they were and are loved and wanted."* Numerous survey comments associated the degree of difficulty

in conception with this intense expression of love and desire. One non-Hispanic white heterosexual participant commented, *"It's the story of how they came to exist. It demonstrates the length we were willing to go to become their parents. It's important for children to know how very much they were wanted and loved from the moment of inception."* One non-Hispanic white heterosexual identified participant stated, *"I just want them to understand how much we wanted them. That we moved heaven and earth and how much of a miracle they are."* Participants' response demonstrates that there is a high perception about the affective importance of disclosure. Furthermore, reference to the parents own reproductive struggle gives more import to the relevance of disclosure.

There is a symbiotic relationship between the narrative about how much the child was wanted and participants' strong desires to become parents. In this context, disclosure was about the decision to use fertility treatment as a means of achieving that objective. As an extension, medical conception also resulted in parents reproducing the child they always wanted. A non-Hispanic heterosexual identified participant commented:

> *First of all, as a single (Christian / religious) woman, it is obvious to most people who know me that my children were conceived with medical assistance and I much prefer that they know this information rather than speculate that I slept with someone outside of marriage.* ***While I used to be very reserved and private about my personal life and relationships, I know want the people that matter to me, including my children, to know that they were brought into the world in an unconventional way because I so strongly desired to be a mom and have a child (in this case, two children.) I found so much support from my family, my friends, and aquaintences [sic] that I can't believe I ever worried about what people think. This experience taught me not to fear and worry***

> ***about what others might think because it could keep me from getting what I really want in this life. I felt and still feel very empowered by making the choice I did and people see me as a strong, brave, and independant [sic] (single) woman who isn't afraid anymore of letting the world know all about something as personal as my children's conception.*** *I've reflected on me as a person, me as a Christian, and me in all my other family, friend and work roles. I don't feel any shame and I don't ever want my children to feel any shame in my choice for their existance [sic] either. I will be as open and forthright as I can be. I started already from their infancy. I also share my story with other single women who desire to be SMBC so they may be able to find happiness too. If my story helps them take the steps they need to, than I see that as an important reason to share my story.*

This participant elaborates on the complexity of disclosure, which for her had to do with religion and marital status. She sees her disclosure as a way of empowering women to also make the choice if their desire is to become a mother. Importantly, especially for my analysis here, is that while her decision to disclose is about communicating with her child how much they were wanted, it is also resistance to perceived disapproval of her mode of conception. She refers to her mode of conception as unconventional and her decision to disclose becomes an effort to buffer any form of backlash that the child may experience as a consequence.

Special was a common refrain in many of the comments left by survey participants. Children conceived through ART are special for a number of reasons based on the degree of difficulty associated with the use of ART – scheduling; processes; financial and emotional costs; the possibilities of science with a share of luck. Disclosure about the use of fertility treatment was an instrumental aspect of conveying this sentiment of exceptionalism; *"so he knows how*

special he is to me" wrote one non-Hispanic white heterosexual participant. Framing the child as *special* referred also to the way he/she was conceived. One Non-white bisexual identified participant also commented:

> *I imagine at some point I'll share with the girls that they had to be conceived in a special way, but I don't see it as that relevant to anything, other than I want them to know how important they are to me, and how grateful I am that the assistive reproductive therapy worked.*

The importance of conception disclosure to children varies from one family to another. For some participants, disclosure is an opportunity to convey to the child how much they were wanted, desired, and special. Establishing emotional attachments to the child was an intricate part, and embedded in the process, of disclosure. The disclosure narrative therefore becomes an imperative bonding experience between parent and child.

HONESTY PERMITS BONDING, SECRECY BREEDS SHAME

Parents' inclination towards disclosure was motivated by an overall desire to be open with their children. Parents believe that openness allows the child to learn about their conception story, normalize it, and such openness provides a counter-narrative against social stigma and averts internalized shame. An Asian heterosexual identified participant similarly commented on the relationship between her decision to be honest and the implications that otherwise contribute to stigma, *"I don't want to lie about the circumstances of his conception and birth, so when he has asked, I answer honestly. I do want to take away the stigma of ART and that is another reason why I would want to share the information. But, because he is biologically our child, I could see how I could get away with not having to tell him if I felt strongly that way."* In the description of participants who report disclosure is important, concealment was always

constructed in the negative. The idea that secrecy produces shame and stigmatization was evident in many of the participants' comments. As one non-Hispanic white heterosexual identified participant noted, *"I don't want it to be a secret and stigmatized."* Two non-Hispanic white heterosexual identified participants commented that *"secrets eat away at families. i would never not tell my child their story"* and *"Secrecy breeds shame. There is nothing shameful here, so no reason for secrecy."*

For some parents, however, secrecy is viewed as a way to protect the child "from the stigma of being different" particularly because "they were not conceived 'naturally'" (Hargreaves & Daniels 2007:420). In a study on donor conception disclosure from an adolescent perspective, the participants described secrecy as being synonymous with shame and for the most part supported that donor conceived children had the right to be told and specifically told by their parents (Kirkman et al. 2007). In other research, parents described their discomfort with keeping donor conception a secret and the labor involved with maintaining that secret (Blyth et al. 2010; Daniels et al. 2011). Parents tend to feel that they compromise their own integrity if they keep conception a secret and report relational as well as emotional problems as a consequence.

Other factors that motivated disclosure to the child included the parents own personal history as an adoptee and their overall practice of disclosure to other persons about the use of ART. When asked about the importance of disclosure, one non-Hispanic white heterosexual identified participant commented, *"I don't think it is especially important, but I believe it is important to be honest and open with our daughter. I imagine when she is older she may have questions about it. I am adopted and was always raised with honesty and openness, and I think that is very important."* For this participant, she drew some parallel between her child's

experience and her own as someone who was adopted. In this regard, the importance of disclosing to the child was part of a more global family practice of openness and honesty.

Establishing a culture of openness and honesty is about preserving the quality of the parent-child relationship. One Asian heterosexual identified participant noted, "*It is important for them to know the truth of how they came into this world. I want to have a close bond with my children and I believe honesty is very important in a close relationship."* In contrast, accidental disclosure was perceived as threatening the quality of parent-child relationships. A non-Hispanic white heterosexual identified participant commented:

> *I do want my daughter to find out that she was conceived through a fertility clinic, and given that it was a pretty standard IVF and no complications with her, I don't think it will be too shocking, especially since it is now a fairly acceptable practice. However,* ***anytime someone finds something out like that and they wonder why their parents or families didn't tell them, it is upsetting, so I definitely want her to know at some point.*** *I think the weird part for her will be that she was a frozen embryo for a year, but we will tell her because I want her to know. It is possible she will need to know for medical reasons as she gets older, as well, so I want her to know anything that might be important there. However, I thought we would have already told her (she is almost 7), but beyond telling her we needed a doctor's help, we haven't yet. This is partly due to the fact that I don't know how she would process that at this age, and also because she goes to a Catholic school where the official line is that IVF isn't acceptable. The church has been coming down hard on certain issues lately, and while I think they are completely wrong, I wouldn't want her to talk about it at school…I don't feel like I need to defend myself to them, and if it got out and the pastor gave us a hard time, I would be prepared to pull her*

> *out of the school without embarrassment...Finally, I thought we would have told her about the other daughter (her sister), but I haven't done that yet. Again, this is partly due to the fact that I don't know how she would handle it at this age. She is very bright, but very sensitive, and easily spooked, and I don't want to scare her…*

As this participant elaborated, they were in between the viewpoints that disclosure was somewhat important and very important. Her story also speaks to the complexity of disclosure in many respects. For her, disclosure concerns the fact that the initial development of the child began from a frozen embryo, which was kept for a year. Furthermore, her daughter's enrollment in a Catholic School, the doctrines of the Catholic Church, and the potential material consequences of conception disclosure created additional anxieties. Yet, as complicated as disclosure is, and even amidst desires not to scare her, concealment is viewed as harmful to the parent-child relationship.

Being openly lesbian, gay, or queer, in and of itself, provoked disclosure for many participants. References to secrecy, honesty, and openness were areas where participants specifically mentioned their sexuality. For sexual minority women, sexual identity shaped the inevitability of disclosure and the impossibility of non-disclosure. One non-Hispanic white lesbian participant commented, "*Since I'm in a lesbian relationship, it will be pretty clear anyway that our daughter was not conceived in the traditional way. But I think it's important to be up front and honest about how our family came to be so that she can feel knowledgeable and prod.*" Another non-Hispanic white lesbian identified participant stated, *"Because we are a lesbian household, there's no point in being vague about how my children were conceived. My son knows that he has a donor and that he has two moms. He's not even 3 yet so we haven't done much discussion of what a donor is, but he is aware that his family has a different structure than*

many of the other families at preschool, and we will continue to be open and honest with him about how he was conceived."

For sexual minority women, particularly those in out lesbian and gay relationships, secrecy can be likened to the fragility of an egg threatening to spill its content with the slightest jolt. Open and honest sharing seemed to be a consequence of their queer visibility in a heteronormative society. A non-Hispanic white bisexual identified participant contributed, "*Having two moms, there will be an obvious need for questions at some point, but I want our son to know that we didn't keep anything from him. Ideally, when asked by friends later on in life when he found out about the donor, etc. He will say he always knew."* A non-Hispanic white lesbian identified participant commented:

> *1. My son's conception story is part of his story--it belongs to him. 2.* ***As an out lesbian with a known heterosexual donor, I felt that it was very important that my son never refer to anyone as "dad," especially the donor…****It was also protection for the donor who was very clear that he did not want to be a dad and could not contribute financially to my son's upbringing. 3.* ***Since I did not want to list my donor on any forms, I knew that we would eventually have to deal with the "who's your dad" question and I wanted my son fully prepared.***

As the previous participant highlighted, being in a same-sex relationship creates an obvious need for disclosure about their child's conception. The latter participant also speaks to the relationship between *being out* about one's sexuality and disclosure. Consistently, LGBQ participants have suggested that disclosure is consistent with a practice of openness as well as a desire to prepare the child to address questions about the structure of their family. I argue that this groundwork is uniquely motivated by a lesbian/gay identity. This is not to say that heterosexual identified

parents are not engaged in the practice of preparing their child to address questions about their conception, however relative to their gay and lesbian counterparts, they are less likely to contend with any random social inquisitions.

THEIR CONCEPTION STORY

Assisted conception was viewed by participants as an important aspect of the child's medical history. One non-Hispanic white heterosexual identified participant commented, *"I think it can be important for if they try to conceive. I also think its part of their story."* As if infertility was genetic and would give birth to future generations of infertility experiences, participants saw disclosure as an important variable in the child's own reproductive future. Another non-Hispanic white heterosexual identified participant commented, "*I believe she has a right to know, will want her to be aware of her own medical history and my history of infertility so that she can make informed decisions for herself."* Open communication about the use of assisted fertility techniques therefore facilitate transfers of knowledge that is importantly linked to concerns about the child's own reproductive trajectory. One non-Hispanic bisexual identified participant stated, *"It is part of his history. It is part of teaching him that all different histories are of value. He could go through it himself someday."*

Parents engaged in open dialogue to share with their children assisted reproduction as an aspect of the child's story. Comments from multiple participants included, *"I think it's important he knows how he got here"* (non-Hispanic White heterosexual); *"I want it to be part of their story, something they always no and is never any big surprise*" (non-Hispanic White Heterosexual); and *"I think every child deserves to know his/her story"* (non-Hispanic White, Bisexual). Another non-Hispanic white heterosexual identified participant wrote, *"If from day 1 you tell them their origins, it is just part of their story then. They won't feel blind sided or hurt*

as they would if they found out when they were adults." For at least this last participant, disclosure was also an important way to eliminate the risk of accidental discovery. Children's right to know about their conception story, medical history, and the best interest of the child rhetoric, particularly to counter accidental disclosure, are not the only existing perspectives on disclosure as demonstrated by research data.

Parents' position on the importance of disclosure to the child varied depending on who was positioned at the epicenter of the conception story – be it the child, siblings, one parent or another, or donor(s). The following comment from a non-Hispanic white bisexual identified contributor speaks to the complexity of donor conception, genetic and non-genetic kinship, and decisions to not disclose as a consequence:

> *In the case of my first pregnancy, I was in a same sex relationship, so there's no masking our use of medical assistance from anyone. / / In the case of my second pregnancy, I am in a heterosexual relationship, and* ***my male partner does not want other people to know that we used a sperm donor. I think he is worried that other people will not perceive him as our daughter's "real" father, and that it's not their business. I do not want our daughter to mistakenly believe that his medical history is hers****, but we have no need to cross that bridge right now. We'll figure that out when she is older (she's only 2 years old right now). When we talk to medical professionals about her health, we reveal how she was conceived. But, for most family and friends, we don't share that information.*

This participant touches on several issues – sexuality and disclosure, male infertility, donor involvement, and the ownership rights of the conception information. Women who experience courtesy stigma often find it more difficult to disclose due to perceived higher level of stigma associated with male infertility (Miall 1986). From this participant's comment, and alluded to by

others who thought that disclosure was not important, donor conception impeded or made disclosure more challenging.

Donor insemination is, therefore, a central part of conception disclosure decisions. While donor conception repressed disclosure for a few participants, it motivated disclosure for others. A non-Hispanic white heterosexual identified participant commented, *"With donor embryo I want to make sure my child always knows his origins and has no surprises down the road."* Another non-Hispanic white heterosexual identified participant added:

> ***my child was conceived thru egg donation and i believe it is absolutely important to the health of the family and to the child to know the truth of genetic origins.*** *if it was simply ivf [sic] with own gametes, i would feel it is virtually unimportant for a child to know, but he would know simply because it would be part of our story and his birth story, but not necessary for his identity.*

Disclosure to donor conceived children is ultimately about raising children's awareness regarding how they came into the world. Participants also conveyed information that is critical to the child's medical history. Another Hispanic white heterosexual identified participant contributed, "*This is a part of my child's medical history; I think that it is an important part of being open and honest about the realities of his conception."* Disclosure is constructed as imperative to the child's health record, simply on account of the mode of conception and for many the involvement of a donor. It is not uncommon for health professionals to question and record information about a person's family medical history in the diagnosis and treatment of certain ailment. Disclosure therefore readied the child for any such future medical encounters and inquiries.

NORMALIZING MEDICAL CONCEPTION

The idea of normalizing medical conception featured prominently in many of the survey comments and in a variety of ways. Disclosure is one mechanism through which participants attempted to legitimize medical assisted conception as another means of conceiving a child or building family. One Hispanic white heterosexual identified participant commented:

> *We longed for our children for so long and in part because of our struggle, we appreciate them every single day. They are our miracles. /* ***More importantly, as my children get older, I think it's important for them to know that not all families are created easily or in the "typical" way. Some parents need extra help like we did, some parents' adopt to grow their families, and some people choose not to have children at all because of their challenges.*** *The expectation of the ease of creating a family is part of what makes infertility so crushing****. If people had broader expectations of how families are made, perhaps the experience would be less isolating for those going through it.***

Interestingly, the participant hints at the connection between the lack of alternative discourse about conception and broader personal experiences as well as the social consequences of infertility. For many women, disclosure is important to their efforts to fold assisted conception into everyday discourse about how babies come into the world or how families are created. This also has some constructive implications for the destigmatization of infertility since the infertility story and experience is inextricably linked to the use of ART for a significant group of women.

Normalizing medical conception was repeatedly mentioned in the context of differential pathways to conceive, have children, and build family. One comment, made by a non-Hispanic white heterosexual identified woman, noted that *"there are many ways to build a family."* Disclosure allowed medical conception to integrate into already established forms of discussion

about, as one participant wrote, *"the birds and the bees and where babies come from."* One non-Hispanic white Lesbian identified participant commented, "*My kids will of course learn where babies come from, i.e. sperm + egg. They will know that neither of their moms could have supplied the sperm, so we'll explain to them how they were created. Plus, everyone else knows, so they should too."* One non-Hispanic white heterosexual identified participant also commented, "*we've never treated it as if it's a big deal. they simply know that babies come in different ways, and they came with the help of a lot of doctors."* This participant normalized medical conception using what Mac Dougall et al. (2007) calls "the helper" narrative to explain their mode of conception (p.528). Another non-Hispanic white queer participant similarly commented, "*Seems to me that families are made in all sorts of ways - this is no different than begin conceived with penetrative heterosexual sex, which I also explain to my children."* Another Black/African American gay identified participant pointed out that, "*It's important for us to discuss the many different ways children are conceived with our kids. Part of that discussion and normalizing it is talking about how they were conceived."* Medical conception is therefore an option among many to bring a child into the world and participants suggest that open and consistent communication was crucial to establishing that.

Mainstreaming medically assisted fertility concerns an open, repetitive, and age-appropriate dialogue about the different ways that a child can be conceived. In contrast, conversations that happen as a one-time event often give the impression that medical assisted conception was an issue or a big deal as one participant commented. Yet allowing the story to unfold over time, establishes it as an ordinary and natural aspect of the child's birth history. Respondents further elaborated on a process of disclosure that was initiated early and reverberated throughout the course of the child's life. This is another way of normalizing

medically assisted conception through recurring conversation. One non-Hispanic white heterosexual identified survey participant eloquently elaborated on the approach to disclosing to children by tempering the conversation about different pathways to parenthood:

> *…Although they don't need to be told all of the details about their conception at a young age, revealing age-appropriate information is essential to helping them understand that seeking assistance with conception is a common path to parenthood. When they are young, it can be as simple as saying* ***"A doctor gave Mommy some medicine to help her get pregnant with you." As they get older, parents can fill in the details so that by the time the child is an adult they can fully understand the process that some people go through to have children****. This will hopefully make them more empathetic to those who have these experiences and help them to cope with the process if they have to go through it.*

Normalizing ART discourse in conversation, both with the child and in other social contexts, is an imperative to destigmatize the use of fertility treatment. One non-Hispanic white heterosexual identified individual commented, "*Information in best normalized from birth. Fight the stigma!"* Incorporating medically assisted conception as part of regular conversations about family building is an intentional attempt by many participants to free it from silences, which signify it as different and dishonorable. A non-Hispanic white lesbian identified participant commented, "*i think they should have a nonstigmatized understanding of the facts."* Another non-Hispanic white heterosexual identified woman commented, "*they need to know that there are options. I want them to be educated and nonjudgemental [sic]."* The unintended consequence of non-disclosure about fertility treatment is that it does nothing to humanize the process or make it less stigmatized. The normalization of ART means dismantling the secrecy

that surrounds its use through ordinary, everyday conversations. One non-Hispanic heterosexual participant stated, *"I want to normalize it. Secrets make it seem like something wrong, which it isn't."* The following comment from a non-Hispanic white lesbian identified participant spoke to such desires:

> *With queer parents, she is going to have to be aware of the fact that there was a "birth other" (Diane Ehrensaft's language) who helped us create her.* ***There is not a way to not have a story for her about how she was conceived. I think it's important for kids to have a lot of narratives about who they are, where they fit, what their family is like, etc; and I see conception as part of those narratives. I also want to create a model for her in being able to talk about such issues without shame as a way to combat any potential stigma she might encounter having two moms.*** *We used a known donor and that was another layer that felt important to us in terms of there never being any secret about who her donor is. We want her to be able to ask as many questions as she wants (or not!) around the story of her conception.* ***We've talked about it a lot; our idea is to normalize it and have it be part of day-to-day so it doesn't feel like a big deal or some big secret to her later in life.***

The participant quoted above brings into view the complexity of disclosure for queer parents and donor conception. In the context of the discussion here, however, the participant concedes the importance of disclosure as a way to share with the child about how she was conceived and providing her the right tools to resist shame and stigma. One non-Hispanic white heterosexual identified participant succinctly stated, *"Important because there is no shame in the game. I want her to feel loved and wanted and proud of how we came to be a family."*

ROMANTICIZING THE SCIENCE

Based on one feminist perspective, many oppose ART on the basis that it is another tool of power to control women's bodies and to hold them hostage to their social role as mothers (Lorber 2000; Strickler 1992). The counterargument from a more liberal feminist perspective is that the technologies allow individuals, who were otherwise unable, "the choice" to biologically conceive and the ability "to decide when and under what conditions" to do so (Rushing & Onorato 2013:397). Not only does the use of ART signify that women were incentivized by the technological possibilities, but as a few survey comments suggest, women were inclined to side with the later school of thought. The *wonder* of the technology, at least for a few participants, became the principal motive to disclose. A non-Hispanic white heterosexual identified participant shared on the survey, *"Because science is fantastic. Why wouldn't we share that with him?"* According to a non-Hispanic white lesbian identified participant:

> *I think it is important to be open about who we are and where we come from. I think kids should know these things as they get old enough because it is a part of our lives. We wanted children enough to go through a lot of medical treatment and I'd like te [sic] kids to know why they were concieved [sic] the way they were and that this is not abnormal. I think talking about it openly makes it normal.* ***I think technology is pretty amazing and my kids are really neat products of love and technology.***

Based on the latter comment, the product of medical conception, the (poster) child, is the living proof of scientific progress. The birth of a child conceived with medical assistance symbolizes the possibilities and success of the technology. In this way, the child's mere existence serves to humanize assisted conception.

Romanticizing the science simultaneously symbolized the treacherous journey to parenthood, and a demonstration of love and *wanted-ness* for the child. According to one non-Hispanic white heterosexual identified participant, *"I gave birth to sons and they will not have the same biological issues when they try to conceive. But I would tell them because the science is amazing and it is proof of how wanted they were."* Similarly, another Non-Hispanic white heterosexual identified woman stated,

> ***I just think it's kind of cool in a science fictiony sort of way... and it shows my son how much we wanted him to let him know how he was conceived.*** *But I don't really feel any sort of ethical or moral obligation one way or the other with regard to telling him. It's just a neat fact to know about oneself.*

Likewise, a non-Hispanic white heterosexual identified participant shared, "*I think it is important for him to know just how special he is and that we were so lucky to have him with the help of science."* Explaining how the technology works and allowing the child to see what is possible, reinforces parents level of determination, and by extension, the depths of their desire to bring the child into the world. A non-Hispanic white heterosexual identified participant commented, *"I think from the scientific point of view is amazing and I wanted to share it with my child! Also she knows that we went through a lot of work to have her, it was not just a romantic evening under the stars, but a decision that involved a lot of efforts."* In a general sense, the technology is definitively and inseparably a part of the child's existence. One Non-Hispanic white bisexual identified participant kept scientific artifacts to demonstrate the capabilities and coolness of science and technology:

> *I think that it is important to show them that they were very much wanted and that we worked hard for them.* ***That their birth story, all the way back to conception, is an***

> ***important part of who they are and how they got here.... and how much we love them. I still have the first photos that the clinic gave us, of the blastocysts, to show them someday. Also that science is cool - and anything is possible.*** *All cheesy things, I know- but I want to encourage them to be the most free and wonderful people that thy can be.*

As critical as women were in other aspects of their anecdotal accounts (Chapter 4), being able to achieve pregnancy was the ultimate goal and was only made possible with modern biotechnologies. Johnson and Simon (2012) uses the concept of "technological salience" to explain that persons will more carefully evaluate biomedical technologies based on their "subjective implications" (Johnson & Simon 2012:264). In my own research, some participants saw assisted reproductive technologies as salient because of its personal impact in resolving their fertility challenges. Participants' romanticized remembering of medically assisted fertility is therefore produced by their successful pregnancy. Disclosure on the basis of how cool, amazing, and fantastic the science is, was not simply just about idealizing the technology, it represented medical, technological and personal triumphs. In this way, participants pointed to the productive possibilities of the technology for themselves as well as for the child if they were to have such infertility experiences in the future.

III. DISCUSSION

Using words such as special, wanted, and love, allowed participants to paint a positive picture about conceiving their child with the help of assisted technologies. Mac Dougall et al. (2007) utilized the theme "labor of love" to label participants approach to disclosure, which emphasized the parents' biological struggles to conceive (p.528). In my research, participants' draw on a similar articulation of love, accentuated with details of their conception and

reproductive labor.[13] However, one point of departure from Mac Dougall et al. (2007) is that not all survey participants in my study used a donor. For this reason, I argue that disclosure is important to communicate to the child their parents' intentionality to conceive, but most of all to provide the child with a positive reference for how they entered the world. Most intentionally, positive references and representations were necessary to contradict stigmatized connotations about assisted reproduction.

The findings in this chapter parallel those from previous research on disclosure as they relate to the child's right to know about their conception information (Hershberger et al.2007; Readings et al.2011). Participants value open and honest relationships with their children and expressed a sense of obligation to inform the child about their conception as constitutive aspect of their medical history. Hershberger et al. (2007) similarly found that disclosure was driven by a desire to maintain a culture of openness and honesty within the family unit. Moreover, disclosure was frequently mentioned as important especially in the context of disapproving secrecy, a self-imposed silencing that renders medical conception invisible. This lack of visibility inspires shame and makes possible the social construction of a normal and natural path to conception while simultaneously constructing an abnormal path. Participants in this study demonstrated that disclosure not only provides children with an understanding of their medical history, but it also gives them a counter narrative to the dominant cultural frames that decry and stigmatize medical conception.

Increasing awareness and disclosure about assisted conception is an attempt to shift the conversation from a place of marginality and unconventionality that will allow persons to achieve some appearance of normalcy. As discussed in Chapter 2, Miall (1986) offers three

[13] I use the term *conception and reproductive labor* here to include the process of getting pregnant, carrying the pregnancy and giving birth.

approaches to strategic information management - selective concealment; therapeutic disclosure; and preventive disclosure. However, based on my data on the importance of disclosure I propose subversive disclosure as a fourth. Conception disclosure for many of the parents in my research is about exposure, evoking a social consciousness to mainstream medical conception as one pathway to parenthood. Disclosure is about subverting stigmatized views about assisted conception through disclosure efforts that lead to visibility and that essentially humanize medical conception. According to Goffman (1963), "the more allied the individual is with normal, the more he will see himself in nonstigmatized terms" (p.107). Despite previous discussions concerning the difficulty endured during the process of fertility treatment, participants had embellished views about the science and technology. Based on these glorified descriptions of ART, it is apparent that some participants did not share earlier feminist concerns that reproductive technologies are apparatuses of control. Similar to the sentimental expressions of love and desire, the idealized view of the technologies can also be viewed in the context of providing an affirmative view of the technologies, especially for children. Such positive frames counter those shared in the controversial Dolce & Gabbana (D&G) social media debacle mentioned in the previous chapter. It is apparent from my research data that individuals are engaged in what Goffman terms "impression management" (Inglis & Thorpe 2012:122). This is evidenced by the claims made that disclosure is important as an expression of love and desire for the child, as well as the romanticized description of the technology all in an effort to legitimize ART as among many options to build a family and fight social stigma.

Stigma, be it perceived or realized, was linked to the importance of disclosure, in that disclosure is an imperative to combating this stigma. Disclosure decisions and practices around medical conception must be understood in the context of a more cultural, and possibly global,

shift in destigmatizing several medical experiences including, HIV/AIDS, abortion, childlessness, and mental illness. In the case of infertility, women do experience it as a stigmatized identity (Greil 2002; Jansen and Onge 2015) and that perceived stigma influences disclosure decisions and practices (Slade et al. 2007). A sense of perceived stigma associated with fertility treatment resonated loudly in the accounts provided by the survey participants and based on my research, participants saw disclosure as critical to confronting stigma. My research data suggest that resisting stigma or challenging "stigma power" was at the fore of some participants' decisions to disclose (Jansen & Onge 2015). Disclosure was deemed important in normalizing medical conception; demonstrating to the child how much they are wanted, loved, and special; and being open and honest with children about their conception story. These justifications for the importance of disclosure, were discussed in the context of fighting stigma whether through de-sensitization; providing the child with the language to speak back to it; or minimizing the possibility that the child will internalize the shame. Participants engaged in open dialogue as a way of disassociating medical conception from shame. Disclosure is therefore a response to, and disavowal of, what participants felt was otherwise a stigmatized condition and identity.

Social stigma aside, conception disclosure is an important aspect of the child's medical history. As if infertility was a hereditary disease, parents felt it important to share in case the child also has fertility challenges of their own. Furthermore, the involvement of a donor gave import to conception disclosure due to the fact that many medical conditions are genetically linked. While parents in other studies have concerns about the ownership of conception information (e.g. Blyth et al 2010) some parents in my research surrendered ownership to the child without any reservation.

Differences in views regarding the importance of disclosing to children were not striking based on sexuality. Both groups made similar comments across the thematic areas discussed in this chapter as demonstrated by the selected quotes. Although heterosexual identified women also desired openness in their parent-child relationships, sexual minority women noticeably made reference to their sexual identity in their explanation about the desire to be open and honest with their child. Being an out lesbian, for example, made conception disclosure inescapable amidst otherwise relentless curiosity from others about their family building technique and the absence of a male/father figure. It appears, therefore, that queer reproduction inevitable attracts attention. One study by Luce (2010) found that lesbian women used their pregnancy to clarify their relationships and to affirm their identity as lesbians. Honesty as well as openness is important to sexual minority women for various reasons – as part of their identity disclosure and coming out story, which further allows the child to understand their own family structure.

IV. CONCLUSION

The quantitative data show that there is no association between sexual identity and perceived importance of disclosing to children about their conception with medical assistance. However, LGBQ identified women appear to place slightly greater importance on disclosure to their children (20 percentage point difference in the category “very important”). From the qualitative responses, I argue that a desire to engage in open communication might explain this slight inclination on the part of LGBQ women to place greater importance on disclosure. Queer reproduction and visibility sometimes demand and require disclosure. As already discussed, being in a same-sex relationship inspires conversation about how one’s child was conceived and makes concealment less of an option either because the parent is out and/or because there is a lack of visible male representation in their family life. Thus, the desire to have an open and

honest relationship with their child(ren) about their mode of conception was, at least in part, due to their sexual orientation for LGBQ identified women and explaining to the child their family structure.

The data and analysis in this chapter aptly demonstrates that individuals who conceive with the use of ART see disclosure as a response to established social norms. Assisted conception has consistently been viewed as separate and distinct from the traditional and normal ways of reproduction and family building. As a consequence, women both experience and view medical conception as stigmatized. Based on many accounts, participants perceive that they have suffered a status loss either due to infertility experience or the use of technologies to conceive. In response, they viewed disclosure as an important practice in destabilizing some of these long held views. What you have read in this chapter, therefore, establishes the importance of conception disclosure in shaping both the child's and society's understanding of medical conception.

This chapter contributes to an understanding of the importance placed on disclosure to children among women who conceived with the use of medical assistance. Curiosity and conversations about where babies come from happens at some point in a child's life. Given this moment of medical conception, it is important to understand how that conversation unfolds when the child is conceived with the help of technology vis-à-vis the typical discourse around sexuality and reproduction. Although distinct dissimilarities did not emerge based on sexual identity, my research provides a window into research on the perceived importance of conception disclosure to children among users themselves. This research ostensibly allows us to understand the association between stigma and the management of conception information and, in particular, stigma resistance as motivating disclosure. Examined as a whole, the discussions here, along

with those in previous chapters, highlight the tensions between the technology and what it makes possible, as well as medical reproduction as stigmatized and at the same time necessary for some persons.

This chapter has its own set of limitations that future research must attend to. First, participants were not asked to share instances in which they experience stigma and so it is impossible to discern whether their stigma references are based on felt or enacted stigma. Additionally, stigma resistance emerged organically across participants' response, but was not directly examined in this study. It is not known for certain how widespread this perception is among persons who conceive with or without the help of reproductive technologies.

CHAPTER 7

CONCEPTION DISCLOSURE STRATEGIES

I. INTRODUCTION

Research suggests that individuals either get no information or conflicting information from medical professionals about conception disclosure to children. In a study by Peters et al. (2005) participants felt ill-prepared and asserted that they would disclose to their children if they had access to appropriate, child-friendly literature. Individuals have also participated in research with the sole purpose of learning from other parents who have disclosed to their children about their conception (Kirkman 2003). In one study by Hargreaves and Daniels (2007) participants indicated that they were advised by the clinic to disclose early, despite participants' own decisions or intentions. Even among parents who had already disclosed to their children, they still desired continued professional support and guidance as well as other material resources, such as books and instructional videos, to assist with ongoing conversation (Lalos et al. 2007). Overall, these studies demonstrate that parents required helpful resources, consistent information, continued counseling and assistance, as well as sought out models for conception disclosure that speak to approach, timing, and language.

Beyond the decision about whether to disclose or not, parents struggle with how to approach disclosing assisted conception information to children. Scholars, practitioners, and agencies have provided some useful strategies for parents who conceive with ART to assist them with framing disclosure conversation with children. Overwhelming, they recommend that disclosure take place early, with compassion, and structured in a very positive way; emphasizing more about the ways that families are created and the role of love in the making of the family, with less concentration on how the child was conceived (The Victorian Assisted Reproductive

Authority 2014). The analysis presented in this chapter, brings conception disclosure to the fore, from the perspective of parents who have disclosed or are contemplating disclosure, in order to advance our understanding about timing and approach to disclosure. In this chapter, I examine three research questions related to my second research objective: *1) Among those who have disclosed what are the strategies employed? 2) Among those who have not disclosed but who intend to, how do they plan on doing so? 3) Are there any differences based on sexual identity in disclosure or planned disclosure strategies?*

Based on the Communication Privacy Management framework, I anticipated that parents' disclosure to their child, planned or actual, would include rules about whether the child was permitted to share their conception information and to whom. However, I find that parents were more focused on timing and content. A focused reading of the 80 survey comments pertaining to disclosure generated two deliberate timing strategies and two conversational approaches to disclosure. Based on my analysis, I have categorized timing strategies both employed among actual disclosers and planned among intended disclosers within two groups: Intentional (Early) Initiators and Opportunistic Seguers. With respect to conversational approaches, which include content and mode of delivery, I have categorized the data in two ways: Straight Talk and Creative Articulations. Conception disclosure is complex and as displayed in Figure 7.1, either of the two timing strategies can be combined with one or both conversational approach. This hints at some of the many facets of disclosure.[14] Based on my analysis, parents in my sample saw the conception story as sensitive and so they took (or planned on taking) a careful approach to disclosure irrespective of how it was (or would be) executed. Although conception information might be deemed as private to most persons, parents did not emphasize keeping it confidential.

[14] As a reminder, all quotes included in this chapter are taken verbatim and so might contain abbreviations, as well as grammatical and spelling errors

Against this background, I argue that family communication theory should make a distinction between sharing sensitive, private or confidential information.

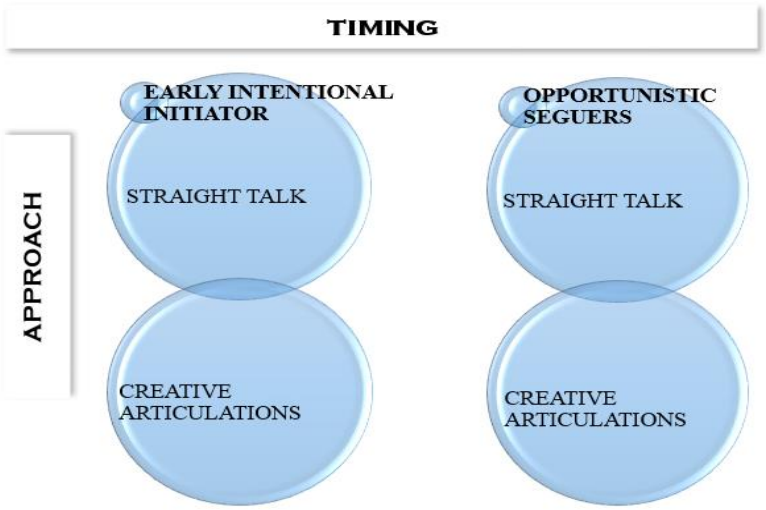


Figure 7.1: Conception discussion strategy among parents who have actually disclosed and intend to disclose

II. RESULTS

ACTUAL DISCLOSURE

TIMING STRATEGIES

1) INTENTIONAL (EARLY) INITIATORS

Intentional early initiators engaged mainly in a process of disclosure at a young age so that the child's memory and orientation to their conception information would be one of familiarity. According to one non-Hispanic white heterosexual identified contributor provided the following, *"they will have heard it from before they understand it. we have books, friends with same family structure, i talk about it in front of him, to him, etc."* These parents are avid believers that sowing the seeds early will help their child to appreciate and assimilate their birth story with greater ease. Initiating conversations earlier, rather than later, heeds to research observations that demonstrate an association between later life disclosure and some adverse outcomes. For example, one study found that parents who waited longer experienced increased

anxiety that the child would find out (Lalos et al. 2007). In another study about decisions to disclose to adult offspring, some parents were remorseful that they had not disclosed earlier and claimed that the wait made it more challenging (Daniels et al. 2011). Based on this existing research, planting the seed earlier and watering it, is more beneficial and associated with a lower risk of negative consequences.

Early initiators were cultivators who attempted to build and normalize conception discussions over time. Comments left on the survey suggest that initiating the conversation early allowed parents to construct and regularize a positive narrative of their conception as well as assist children with developing the language to talk about their own history. According to one non-Hispanic white heterosexual identified participant, "*I read books and we talk "normally" about it in everyday conversation. this narrative building will continue as she ages and begins to inquire more."* Like this parent, other participants referred to disclosure as a work in progress. They used the metaphor of building or implied it by stating that they started small, incrementally adding more details as the child aged. One non-Hispanic white heterosexual identified participant commented, *"Start small, letting them know when they ask about where babies come from that mommy and daddy needed the help of a doctor and increase details as they get older."* These references demonstrate that some individuals did not see disclosure as a one-time event or a "stage production," but rather they sowed into the process early and continued the dialogue as the child aged (Ehrensaft 2005:215). Disclosure for this group, therefore, unfolded in layers (Hersberger et al. 2007), following an "evolutionary progression" where information sharing is customized to align with the child's cognitive development (Ehrensaft 2005:209).

What distinguished women who engage in early disclosure from others is that they are intentional in their efforts to engage in conversation with the child at a very young age. Among

the many reasons these parents were inclined to disclose included establishing an honest and open relationship so that the child always has a knowing about their origin (see Chapter 6). For the early initiators, disclosure was more of a mini-series, which allowed the storyline to develop over time and less of a blockbuster movie event. This strategy allows children to grow up with their conception history.

2) OPPORTUNISTIC SEGUERS

Some participants were less deliberate in their timing of disclosure, allowing the conversation instead to occur naturally or casually. One non-Hispanic white queer identified participant commented, "*We now bring it up casually as it seems relevant, often if we encounter (in books or TV) families different from ours or talk that naturalizes mommy/daddy arrangements. We've talked about when our child is older, making a book that tells her conception story."* Uniquely, one non-Hispanic white heterosexual participant's own published story spurred the conversation. She commented, *"It was in People Magazine and she was reading before she was 2, so disclosure occurred when the article appeared and she saw it."* Their retelling indicated that disclosure was not premeditated, but instead emerged spontaneously and organically in conversations or that disclosure was inspired by other often related events.

In some families, parents drew parallels to other related issues in their conversations about their child's conception. Participants' desire to have another child or their knowledge of other adults' pregnancy, for example, were used to bridge conversations about their child's own creation story. One participant, who identified as a Black/African American lesbian, commented:

> ***We told him what we were doing to try to get pregnant again*** *becuase [sic] the Dr visits interrupted his life as well and that lead to a conversation about what we did to get*

pregnant with him. He was probably a young 4 year old when we started having conversations about it. ***At the time a good friend of his got a new sister so we also talked about how she was conceived (in a straight couple who did not need medical help) and how that was the same and different from our story.***

Another non-Hispanic white bisexual identified participant also shared that she began discussions with her children when she was trying to have a third child. Contemplating future pregnancies created the perfect segue into conversations about the child's own conception story.

Children's curiosity about where babies come from also prompted conception disclosure. A non-Hispanic white heterosexual identified participant commented, *"We discussed it when they first asked from where babies come."* In another example, a non-Hispanic white heterosexual participant commented, *"I share about it when it naturally comes up. He is only three, so this is when he asks questions about babies, pregnancy, etc. We bought a kid book about donor embryo and have told him how the doctors helped put a seed that another couple gave us in mommys belly."* Ehrensaft (2005) advocates for early disclosure within the first two years of the child's life or during the preschool years when children express curiosity about how babies are made; though Ehrensaft warns that waiting for the child to ask potentially places too much pressure on the child to pursue their own origin story (193-194). Children's curiosity about where babies come from can hypothetically impact parents in minimally two ways; it may serve as an indication that the child is ready, while on the other hand it may leave parents feeling like their back is against the wall.

Parents within this category exhibited less deliberate strategizing about the timing of disclosure and took advantage instead of any available window of opportunity. Parents used their own, and other persons' family building efforts as well as the child's curiosity about where

babies come from as springboards to have discussions about conception. This is not to say that opportunistic seguers have lower desires to disclose relative to early initiators, but it does suggest that they have less desire to control the timing and manner of disclosure.

CONVERSATIONAL APPROACH

1) STRAIGHT TALK

A number of participants took a direct approach in discussing conception with their children. They approached the where-babies-come-from-talk as matter-a-fact. One Hispanic white heterosexual identified participant in response to the question about how she disclosed wrote, *"With very clearly explained facts."* Another non-Hispanic white heterosexual identified participant wrote, *"I told him matter of factly."* These participants valued providing their children with an explanation about human reproduction without any ornamentation. According to one non-Hispanic white bisexual identified participant, who had already disclosed to their child, *"It will always be talked about openly. We are not going to skirt around any issues (or substitute any words i.e. penis). It's just easier to be open and honest about it. It will make the inevitable "where do babies come from?" discussion that much easier.. and will put off the "birds and the bees" until a more acceptable age! Win win."* Another non-Hispanic white heterosexual participant shared, *"can't even remember. i think they asked how they were made, and we told them. just very matter-of-fact."*

Participants who engaged in straight talk gave their child very frank and specific details about conception to include IVF, donor, and sperms for example. Scholars have found that some parents are reluctant to include third party involvement for a variety of reasons: to shield the non-genetic parent from rejection, protect the child in cases where the donor is unknown, and protect the child from overall public scrutiny (Kirkman 2003). For many participants engaged in straight

talk, the term donor as well as information and photographs about the donor were incorporated into the child's conception narrative. Specific references to the donor can be seen in several other quotes sprinkled across this chapter. Contrary to the findings from other studies that suggest parents withhold donor information as a protective strategy, the parents in my study engaged in this direct conversational approach that included specifics about assisted conception. A non-Hispanic white bisexual identified participant explained, *"For my son, it's simple. I tell him that his other mom and I wanted to have him so we bought sperm and had a doctor put the sperm inside me so that we could create him. If he ever has questions about the donor, we have the donor's profile and medical history available for him."*

Engaging in inventive story telling or babble-babble-baby talk was an unlikely strategy for these parents. Neither did these parents censor conversations about their process of conception or reproduction in more general terms. As discussed in Chapter 5, exposing children to the details of their conception was one way parents sought to make medical conception a part of normative discourse on reproduction and the topic less taboo. A non-Hispanic heterosexual identified participant commented, *"When they were early teenagers, we discussed "test tube babies," and I related that their father and I wanted children so badly but weren't able to have them, so we needed the doctors to help us create them."* Parents in my research emulate what Ehrensaft (2005) encourages parents to do: "Construct a narrative around the straightforward information that the child was conceived with the help of medical personnel, donors, surrogates, reproductive procedures-in whatever combination applies" (p.211).

What distinguished straight talkers from the other group is that they were very straightforward in their delivery of the conception story. They gave unembellished accounts, which included facts about sex and reproduction. Metaphorical descriptions like the proverbial

baby being delivered by a stork or even fairy tale explanations about reproduction that included a romantic love story was not a feature of the straight talk narrative. Instead these parents emphasized human reproduction and modes of family building. For women in this group, the timing of the conception talk could be deliberate, but could as well be prompted by the child's questions or other related events.

2) CREATIVE ARTICULATION

Other parents approached the conversation more creatively with the help of anecdotes, songs, or more whimsically. One non-Hispanic white heterosexual identified participant commented, *"We talk and joke about were [sic] we was convenience [sic] we drive by it frequently. He doesn't understand now, but we continue to talk about it so it is not a surprise later. He was the "lucky straw." Ok, bad joke."* One lesbian identified and another bisexual identified participant quoted elsewhere in this chapter, admitted to crafting songs that incorporated conception information. Being creative has the potential to alleviate some of the associated anxiety pertaining to conception disclosure, offers a more palatable format for children to digest, and can help make light of a situation that is otherwise challenging.

Parents are creative also in the way they construct their conception story. Language is a critical aspect of disclosure about assisted conception – and not just about reproductive parts and the process, but also with respect to the involvement of third parties. Many parents in the survey cleverly used words such as gift and help from either a woman, doctor or donor in the conception narrative. Such descriptions are also consistent with professional recommendations for parents to use positive frames when engaging in conversation with children about conception. Ehrensaft (2005) coined the term "birth other" to refer to third parties, surrogates as well as egg and sperm donors. Lalos et al. (2007) similarly identified common words to include "a kind man" in

disclosure narrative (p.1762). In another study by Kirkman (2003) participants included language such as "different daddy" and "a kind woman" (p.2235, 2237). Although using such language might soften the effect of the disclosure in the onset, it does not necessarily absolve the parent of any responsibility to further explain what is meant by a gift or who that helpful person was.

Parents relied on conversational props to assist with disclosure, particularly for children at younger ages. As an example, some parents solicited the help of children's books to assist them. One mixed race heterosexual identified participant shared that she disclosed with the help of *"Children books, sharing the experience in age appropriate chunks."* Another participant, who identifies as a non-Hispanic white heterosexual, also commented on the availability of books to assist parents with how to explain medical conception to children. She commented, *"In age appropriate manner starting when they are young. There are many great books out there for kids concerning origins from Reproductive therapies that are a great way to start out the conversation."* To date, there are a number of picture/storybooks dedicated to explaining assisted reproduction to children in ways that parents have found helpful and which makes it easier for young children to understand.

Straight talk was certainly a more popular delivery approach among parents in my study. However, given the anxiety that parents experience when deliberating disclosure, it is not surprising that some parents attempt to make light of the situation through humor or more imaginative approaches. Despite professional recommendation, disclosure of conception between parents and their children is a private matter with real consequences for the well-being of individuals and the family unit. Parents can therefore be expected to act and respond based on their level of comfort and given their own assessment of what is necessary or possible.

STRATEGIES TO DISCLOSE IN THE FUTURE

Participants who intended to disclose and had well-defined ideas about how they will approach it, can be classified under one of two groups: intentional initiators or opportunistic seguers. Despite whichever group participants are assigned to, they either intend to use a straight talk or creative articulations as their conversational approach. Intentional initiators expressed plans to deliberately disclose. For example, a non-Hispanic white heterosexual participant commented, *"I think we will start slowly, with some books, and gradual fill in information. It's a bit complicated for a little kid."* Participants classified as opportunistic sequers were those who indicated that they would have the conversation if they were asked or if it came up. A non-Hispanic white bisexual participant commented, *"When it comes up as part of natural question/conversation about conception. Let him know that it ca happen with or without medicine. Explain the biology."* Another non-Hispanic white heterosexual identified woman stated, *"When they start asking about how babies are made I will tell them that sometimes a doctor helps couples make babies. We are a few years away so I will buy a story book for young children about the subject."*

When it comes to conversational approach, among those classified as straight talkers, all intend to construct a conception narrative that is uncomplicated, unadulterated, and honest. One non-Hispanic white lesbian identified participant provided the following comment, *"Just going to tell them, like we do others. We'll tell them we ordered the sperm online, took eggs from both mommies, and made them and them put them back in Mama until they were born. We'll be straight-forward with them."* Another Hispanic white lesbian identified participant commented *"facts, egg + sperm, with doctors help…."* Those who intended to use a creative approach expect

to execute conception talk with the use of songs or with jokes. A non-Hispanic white bisexual identified participant commented:

> ***We will reference the donor from the beginning, through jokes and casual references..*** *At the right developmental stage, we will provide our child with the full file of infomration [sic] that we know about the donor and have it accessible for him to see whenever he wants. But we will let him bring up questions from there.*

I want to also highlight that among participants who had not yet disclosed, but who expressed future commitments to do so, there was a substantial amount of uncertainty about exactly how disclosure would take place. In response to the survey question about how participants intend to disclose, a few wrote: No idea, I am not sure, and I don't know yet. Uncertainty about how to broach the conversation with children, a lack of confidence and preparedness are some of the many reasons parents were usually cautious about disclosure (Daniels et al. 2011).

The literature suggests that the age of the child is an important variable in decisions about disclosure. As previously mentioned in Chapter 5, participants were not specifically asked about the age of the child conceived with ART. Several participants referred to an appropriate age at which they would disclose to their child, but remained vague about what that exact age was. Other participants referred to an appropriate age or when the child is old enough to understand conception and reproduction. One Black/African American heterosexual identified participant wrote, *"Not sure. I just know that we will wait until they're old enough to understand traditional conception first before we try to explain how they were conceived."* One non-Hispanic white heterosexual identified participant included, *"I imagine when the girls are old enough to understand how reproduction happens that their dad and I will tell them."* Another white lesbian

identified participant commented, *"When the kids are at an appropriate age we will explain how we were able to get pregnant."* Studies have found that parents initiate conversation with their children as early as 3 years of age (Blyth et al. 2010). Mac Dougall et al. (2007) found that persons engaged in a seed-planting strategy embarked on the process of disclosure between the ages of 3 and 4 years of age, either because they had been prompted by a question from the child or did so voluntarily. Additional studies have found that majority of participants, who had disclosed, did so before the child was three years old (Lalos et al. 2007; Rumball & Adair 1999). Lalos et al. (2007) found that the average age of the child among those parents who had disclosed was also 5 years of age. A study by Gottlieb et al. (2000) found that among parents who had disclosed, the average age of those children at the time of disclosure was 5.5 years.

In my research, there were few participants who identified an exact age, moment, or period that they would engage their children in a conversation about their conception. One non-Hispanic white heterosexual identified participant wrote, *"I private conversation when they are older, around age 14."* One non-Hispanic heterosexual identified participant provided the following survey comment, *"When he has a serious girlfriend, or is an age where his is considering children, I will tell him. Unless there is a reason for it to come up sooner."* Based on earlier research, waiting longer to disclose might prove less than beneficial to these participants. One study of donor conceived children found that disclosure at older ages was more associated with children feeling anger, shock, and relief (Jadva et al. 2009). The researchers found that children who were told earlier in their childhood were less likely to report feeling betrayed, anger or feeling different towards their parents.

HYBRID APPROACH

Although I discuss the timing and approach separately, I do so to provide the reader with as clear a classification and description as possible. In reality, however, conception disclosure is

intricate and women did not simply employ a single timing and conversational approach. As previously stated, there is no singular prescription for disclosure to children; parents often get mixed recommendations about what to do and how to go about it, feel ill-prepared or receive no information at all. As a consequence, many rely on their own sense of what to do and how to go about it.

A point of clarification is that, based on my analysis, women who are opportunistic seguers might still disclose (coincidentally) at an early age. My analytical focus on the timing of conception disclosure, however, is about the intentionality versus happenstance. Furthermore, as demonstrated by the diagram in Figure 7.1, early initiators or opportunistic seguers can also employ either or both approaches - straight talk or creative articulation. Take as an example this non-Hispanic white lesbian identified participant who stated, *"Since his birth, I've talked about his donor, using the language of "your donor." The story was that his donor gave me the gift of sperm donation so that I could get pregnant. I can't even remember the first conversation, since it's always been a part of y [sic] son's story."* This participant was both an early intentional initiator and also more direct in her approach using terms such as donor and sperms but still softened the language with the use of terms such as "gift". The following non-Hispanic white heterosexual participant however, was an opportunistic seguer - inspired to disclose because the child questioned where babies come from but with respect to conversational approach was very straightforward. She shared, *"When she asked me how babies are born I explained the different ways that it happens, I explained intercourse and I explained IVF."* The following non-Hispanic white heterosexual participant was more of an early initiator, used a creative conversation approach utilizing books published and created to assist her with conception disclosure. She commented, *"It is a work in progress as he is only 3 1/2. But I have books about families created*

with IVF and I made one using Shutterfly about the trip for my DE cycle. I answer his questions honestly and within age appropriateness. I am his mom. 100%. But it took (plus!!) people to make him. Me and two amazing donors."

VARIATIONS BASED ON SEXUAL IDENTITY

Across the chapter, there are examples from both heterosexual identified and sexual minority women either within the timing, conversational, or the hybrid approach. As already discussed, intentional early initiators engaged in conception talk early to ensure that the child grew up always knowing the truth. Intentional early initiators temper the conversation, mostly adding layers as the child got older. Heterosexual identified women, classified within the group opportunistic seguers, were inspired to have the conversation when asked about where babies come from as were sexual minority participants within this group. Similarly, within the conversational approaches both groups employed either a direct approach to include specifics about the donor as well some creative tactics like using songs, books, and humor to assist with conveying the information. Where comfortable, parents irrespective of sexual identity, took a hybrid approach to conception talk.

For sexual minority parents in particular, however, explaining their own family structure was also a necessary part of disclosure and often included information about donor conception. One non-Hispanic white lesbian identified participant offered:

> *We have already been giving her stories about how she was made. We have the book "What Makes a Baby" and* ***we talk about the specifics of who made her when we read that. We also made up a lot of songs for her when she was a baby - and one of them references the fact that a friend of ours is her donor. Not completely connected to conception: but we also do books with a variety of family structures and talk about the***

> ***fact that she was two moms (and point out her other friends that have two moms and friends tha [sic] have a mom and dad, etc).*** *That's pretty much it at this point.*

Also included in the discussion is further explanation about different family structures to include comparisons between their own with two moms and that of others with a mom and dad. These individuals seized opportunities to have the conception talk when occasions presented themselves either through questions or were prompted by other fictional or real families. One non-Hispanic white queer identified participant commented, *"We now bring it up casually as it seems relevant, often if we encounter (in books or TV) families different from ours or talk that naturalizes mommy/daddy arrangements. We've talked about when our child is older, making a book that tells her conception story*." Comparatively, heterosexual identified parents spoke not about different family structures, but instead explained different family building options that include sex and ART. For example, one non-Hispanic white heterosexual identified participant commented:

> *The topic naturally came up recently when I was talking to my children about where babies come from. One night at bedtime we were reading together and the topic of genes came up.* ***We were discussing how every person is made of genes from the egg and the perm, which led to the children asking how the egg and sperm get together in the first place. That provided an opportunity to talk about how that can happen through sex or that a doctor can help it happen by removing the eggs and sperm, putting them togeter [sic], and then inserting them back into the woman's uterus where the fertilized egg may grow into a baby****. Of course, they asked which way I had gotten pregnant with them and I simply told them the first time the doctor had to help but the second time it was't [sic] necessary. I followed up on the conversation the next night by sharing a children's*

book with them about the topic. ***They seemed satisfied with my straightforward response and have not asked any further questions -- yet!*** *Before this conversation, I ad [sic] worried about how I would disclose this information but in the moment it worked out fine. I think I was more nervous telling them about sex than disclosing that we had sought medical assistance. The disclosure was easy after explaining sex.*

Among those participants who intend to disclose, most either planned on using a straight talk approach or were still unsure about exactly how they would go about it. Sexual minority women anticipate sharing donor information with their children, their desire to have kids, and how they were able to accomplish that or simply engage in matter of fact conversations about how their family was built. This did not differ substantively from the expressed intentions of heterosexual identified straight talkers.

III. DISCUSSION

It was evident, at least for the early initiators, that disclosure happened at a very young age close to birth. Interestingly, women who had not yet disclosed, but who intended to referred cryptically to an appropriate age, vaguely defined around the time that the child has the cognitive dexterity to learn and understand human reproduction and the complexity of their own coming into existence. Although very few participants made any reference to the age of the child in their talk about their disclosure experience, studies have found that disclosure happens across different ages. Majority of the adolescents who participated in the study by Kirkman et al. (2007) suggested that disclosure at a younger age was better, but importantly that parents should determine timing based on their own knowledge of their children. Participants also suggested that irrespective of when disclosure takes place, the window of communication should remain open and children must be invited to ask questions if, and when, they desire.

ART conception disclosure and where-babies-come-from talk was sometimes approached as one in the same conversation. As a consequence, many opportunistic seguers were prompted to begin the discussion to satisfy their children's curiosity about where babies came from by bridging the two conversations. Parents construct responses to include the many ways that families are constructed through adoption, sex, syringes, love, with or without medicine, and sometimes involving help from a third party like the donor and/or doctor. Such conversations also included discussions about eggs, sperms, embryos, and sex.

In recent years there have been a number of published autobiographical accounts about conception with the use of ART and practices of disclosure to children. Additionally, there has been a growing concentration of children's books that explain where babies come from and provide helpful scripts as well as other useful resources for parents. In Hargreaves and Daniels (2007) research, several participants referenced books such as *My Story* and *How I began,* and like a few participants in my study, some created their own books to aid their process of disclosure. Irrespective of whether participants had already disclosed or not, books were important resources in the building and execution of conception talk. At least one participant in my research specifically named the book, "What makes a Baby," which is a picture book designed for preschoolers to children eight years of age. This particular book incorporates different kinds of families – through ART or natural conception with single, LGBT, or heterosexual parents.[15] Other storybooks that explored donor egg conception as well as origins from reproductive therapies, though unnamed, were descriptively mentioned. Other participants created their own to include pictures of embryos, ultrasounds, and other parts of the process. Such books provide parents with a launching pad to begin the conversation with their children

[15] Silverberg, Cory (2012). "What Makes a Baby". Retrieved August 8, 2016. (http://www.what-makes-a-baby.com/)

and may suffice as the ultimate script depending on the circumstances. Given the complexity of the issue and the associated anxiety experienced by parents, agencies such as the London-based *Donor Conception Network* offers, at a cost, "Telling and Talking Workshops" geared towards heterosexual and lesbian couples as well as single women.[16]

The groups I discussed in this chapter are similar to three schools of thought on disclosure as described by Ehrensaft (2005). The three are: 1) Baby's Born, It's Time to Tell; 2) Wait for the Birds and the Bees; and 3) School Age is Prime Time.[17] The first suggests that parents begin discussion even before the child can comprehend the information so that their story becomes and remains a normal part of their growth and development. In this "tell-as-early-as-possible" perspective, parents are advised to ensure that family bonds are secure, which is even more critical when a third-party donor and/or gestational carrier is involved (Ehrensaft 2005:184). This recommended approach is very similar to the parents in my research categorized as intentional early initiators. The second school of thought suggests that around the ages of two and five years old, when a child is more curious about where babies come from, is the time to have the conversation. The advantage, she claims, is that by this time the child is at an appropriate developmental stage to be able to comprehend simple information about conception and reproduction. Another advantage is that there would have been greater, and more significant, family ties developed with the child. The third, "wait-until-school-age" perspective, suggests that disclosure should happen between the ages of seven and ten at which time the child is at "optimal receptivity" to understand the circumstances of their conception and birth (187). She advises that parents disclose when they themselves have reached a state of emotional acceptance and have the "equanimity" to begin talks about the child's birth story (182). The latter two

[16] Donor Conception Network. Retrieved August 5, 2016. (http://www.dcnetwork.org)
[17] Ehrensaft (2005) also identifies a fourth perspective on disclosure that suggests "holding off until adolescence" (p.189).

combined is reflected in the group categorized as opportunistic sequers. As already stated, these are parents who tend to embark in conception talk when prompted by questions from their children presumed to be of school age.

Other scholars have identified similar strategies employed by parents who disclose conception information to their offspring. Mac Dougall et al. (2007) identified two: *"seed-planting"* and *"right time." Seed-planting* referred to telling children from an early age so that they always have knowledge and an understanding of their conception story, making disclosure a process and less of a one-time event. The *"right time"* strategy was based on a premise that a "window of opportunity" would emerge when the moment was right (527). Seed-planters resemble my own concept of intentional early initiators in many respects. However, I found that opportunistic sequers in my study took advantage of windows of opportunity, but did not make any reference to a right time.

Timing strategy is only one aspect of conception disclosure. Based on my analysis, parents expressed more details about the approach to disclosure, which I have classified as either straight talk or creative articulations. A close examination of the data suggests that the lines of demarcation between conversational approaches are less distinct from the timing strategies. Following arguments that disclosure is not a one-time event, but rather a work in progress, parents may decide on different conversational approaches or even a combination of approaches given the circumstances.

From a symbolic interactionist perspective, conception disclosure among ART users is of critical importance for minimally two reasons: meaning making through discourse as well as communication processes; and the impact of conception disclosure on the child's identity development. Although parents are the chief architects of conception talk, narrative building

takes account of and responds to social norms that shape understanding of family and reproduction. In this way, parents make distinctions and highlight similarities between that family and ours or between the way the child is conceived and the way other babies are conceived. Furthermore, the family is a site of social reproduction and as discussed in Chapter 6, disclosure is critical to establishing and normalizing their family while destabilizing dominant tropes of a natural, normal family. During disclosure parents also engage in a process of naming and defining familial and social relations between other key parties – siblings, mom, dad, and donor for instance. Importantly, as the child develops and deploys their own narrative, they further help to create meaning and shape further discourse about the family. Conception disclosure is motivated by parents' desire to inform children about their origins, which is a crucial aspect of their identity development. Studies have found that children who are told at older ages often expressed that they were always haunted by a feeling that they did not belong and associate that to other issues - emotional, relationship, identity, and self-development (Kirkman 2003).

Based on the Communication Privacy Management Theory (CPM), one would expect that parents were preoccupied with deciding to share, setting boundaries about who to share with, and managing conception disclosure or rather protecting against accidental disclosure. This perspective rests on the notion that the information, in this case medical conception information, is regarded as a secret that should be protected. Instead, however, I find that parents were more engaged in a process of managing sensitive information, which required some thought and care about how to engage in discussions with children. Among those who have disclosed or intend to disclose, there was no mention or concern about what the child would do with the information. Instead parents emphasized finding ways to disclose to children so they understand and just an

overall desire for the child to know their history. As discussed in previous chapters, a large proportion of women in my study view conception disclosure as important and have disclosed to either to their children or someone else in their professional, social, or familial networks. I find that the parents in my study have a social activist orientation and so sharing the information was a means of bringing awareness, improving understanding, and destigmatizing assisted conception. The idea of privacy and building protective boundaries around information sharing is therefore counterproductive to this effort to normalize and destigmatize assisted conception.

IV. CONCLUSION

Overwhelmingly, parents in my study had either already disclosed or had expressed a commitment to disclosing. Disclosure happens within the context of parents own confidence to purposefully broach the subject; children's ability, curiosity, and understanding; and relationships as well as other issues pertaining to the family structure (e.g., donor arrangements and single/lesbian/gay parents). According to my research, the disclosure script sometimes included specific reference to a donor while other parents inserted mild words and labels such as a helper and gifts. At times, disclosure was executed with a bit of humor, anecdotes, songs, and photographs. Although there is some common refrain from the comments participants chose to leave on the survey pertaining to their disclosure experience or intention, my data presents no solitary prescription that parents follow. Instead, they were driven by their own desires to disclose, and what they had learnt and then executed (or planned to) the best way they knew how. Many parents relied on books, resources, some professional guidance, and their own intuition to assist with constructing and executing their child's conception narrative.

I hypothesized that sexual minority women would be more likely to disclose on the basis that the visibility of their family structure would encourage, if not force, them to do so.

Consistent with this hypothesis, I expected sexual minority women to not only initiate the conversation early, but also continue the conversation overtime to normalize their family structure. Instead, sexual minority women employed a number of different approaches. Still there is evidence that they were very likely to be inspired by and to include information about differences in family structure. The sample size for this project did not allow for more detailed analysis based on the sexual and gender identity of the parents, studies with larger samples should continue to explore these differences.

Of the 80 comments left on the survey pertaining to the experience of disclosure or intended approach, 70% could be classified within one or a combination of approaches discussed in this chapter. As a reminder, this analysis was based entirely on volunteered responses as participants were not intentionally prompted, in any way, with respect to these approaches and did not self identify within these groups. Approaches to disclosure were based on emergent coding analysis of participants' telling of their disclosure intentions and experiences. As a consequence, there are groups that overlap and more specifically individuals who employ a hybrid approach.

My data adds to ongoing research on disclosure strategies and responds to calls for more experiential accounts in order to learn from others. Although there has been substantial research, impactful legislation, and significant conversation about ART and donor conception disclosure, there is still a dearth of longitude research that examines the effects of different disclosure approaches. Studies must therefore attend more to the children's own account and reaction to being told about their conception through ART. Future studies should continue to examine differences based on modes of conception. Studies should also examine disclosure approach and the effect on relationship quality especially where conception involved the help of a donor.

Although the findings here contribute significantly to discussions on conception disclosure, there are a few key limitations to be noted. One limitation is the possibility of recall error for women who have already disclosed; this is especially true depending on the length of time that elapsed between the completion of the survey and the act of disclosure to the child. It is important to remember that for future disclosers the analysis is based on anticipated actions and were not rooted in lived experiences. Although things do not necessarily happen as planned, disclosure about conception to children among persons who have used ART can feel like a mammoth task requiring much thought and planning. Thus, understanding how parents create a blueprint plan for conception disclosure offers some insight into disclosure decisions, planning, and execution.

CHAPTER 8

CONCLUSION

This study examined the experiences among ART users within the medical encounter and further explored conception disclosure attitudes as well as practices among parents who conceived with ART. Access to parenthood is influenced by structural factors and has been particularly challenging for some populations based on sexual identity, race, socioeconomic status among other socio-demographic indicators. Some of these challenges are even more salient when we look at assisted reproduction. The two major objectives of my research were: First, to explore and analyze variations in the experience of fertility treatment process based on sexual identity and second, to examine the importance of conception disclosure to children as well as differences in attitudes towards conception disclosure and disclosure behaviors based on sexual identity.

Consistent with the stated research objectives each chapter was associated with a specific set of research questions. Chapter 4 examined the experience of fertility treatment and the research questions were as follows: *1) How do individuals undergoing fertility treatment experience the medical encounter? 2) Does the experience within the medical encounter vary based on sexual identity?* For Chapter 5 predicting disclosure and examining disclosure behavior the research questions were as follows: *1) What are the underlying dimensions of disclosure attitudes about assisted conception? 2) Are there differences in disclosure attitude or behavior based on sexual identity? 3) What factors predict conception disclosure the child?* Chapter 6 examined the importance of conception disclosure with the following guiding research questions: *1) Are there differences in the perceived importance of disclosing to offspring about their conception between heterosexual and sexual minority identified women? 2) What are the factors*

that inspire disclosure to offspring? 3) Do these factors differ on the basis of sexual identity? Chapter 7 discussed the experience of disclosing to children and the research questions which guided this chapter's analysis were as follows: *1) Among those who have disclosed what are the strategies employed? 2) Among those who have not disclosed but who intend to, how do they plan on doing so? 3) Are there any differences based on sexual identity in disclosure or planned disclosure strategies?*

I used data from an originally designed online survey to explore differences based on sexual identity among parents who live in the U.S., have successfully conceived using ART, and have given birth to at least one child (N=114). In this concluding chapter, I summarize my research findings, reflect on my research, and highlight opportunities for future research. In Chapter 1, I elaborated on the significance of my research and so in this my concluding chapter I end with a final note highlighting the main findings of my dissertation research.

I. SUMMARY

My research engages a conflict theory perspective, feminist scholarship, and the medical consumerism framework to discuss individual experiences within the medical encounter for fertility treatment. Data highlighted in Chapter 4 shows that physicians continue to hold significant amount of power within modern reproductive medicine. Physicians act as gatekeepers, determining who can gain access to ART, and they also use their professional influence to control who should or should not become biological parents. More recently, healthcare professionals have employed the concept medical consumer to describe patients as rational decision makers. In this way, patients engage in research about their health condition to act in their own best interest and to chart their own desired treatment plan. My research shows that fertility treatment is not exempt from medical consumerist behaviors. Fertility patients do

not simply accept the sick role and present as submissive to physicians and their instructions. Instead, patients insisted on being heard during their treatment process and sometimes terminated treatment relationships where they were unsatisfied. Often patients act in response to lengthy treatment processes, non-negotiable treatment regimes, unsuccessful outcome, and unexplained infertility. The discontinuation of service is an important form of resistance for fertility patients who feel either marginalized during the process or minimized to their biological and reproductive capacity. ART, however, is a specialized area of medicine with a smaller network of physicians and clinics, which means patients do not simply make the choice between voicing their opinion and discontinuing treatment relationships. Given the investment of time and money, as well as the options available, some patients capitalized on opportunities to influence treatment and to create compromise. I see these individuals as agentic medical consumers in many ways, who through research, act as medical associates who are influential contributors in their treatment process.

In Chapter 5, I outline that there is a plethora of reasons why parents choose to disclose to children or not. I find that when all the factors are considered there are two fundamental influencers; disclosure is motivated by an overwhelming sense of care for the child and suppressed by feelings of fear. A statistically significant difference was found on the fear non-disclosure factor and showed that non-disclosure was driven by fear more so for heterosexual identified parents than it was for those who identified as LGBQ. When it came to disclosure to persons within familial, social and professional networks, parents made different decisions about who they would share their child's conception information with. Family doctors, family, and friends were among the persons most included in the circle of trust while there appear to be less interest in disclosing to the child's school or nursery. Less than half of the parents who

participated in my research had disclosed to their children. Based on the data and analysis, I argue that heterosexual identified women were more selective about who they decided to share with. Grounded in a symbolic interactionists framework, I speculate that this is a strategy employed to safeguard against any stigma associated with infertility and medically assisted conception by giving the appearance of normal and thus fertile. According to Gamson (2015), "If becoming a parent suddenly raises your status, revealing that you got there in a nonnormative way can suddenly reduce it" (p.207). For sexual minority persons both the method and family structure are nonnormative. However, the politics of sexuality and reproduction possibly encourage disclosure to more persons and a wider cross-section of persons to give queer reproduction more visibility.

The influence of social norms on disclosure decisions became more apparent in Chapter 6, which discussed the importance of disclosing to children. Parents saw conception disclosure as an important way to demonstrate to their children how much they were loved and wanted. In addition, parents felt like ART was a part of the child's medical history and lauded the technology for what it made possible. Parents also expressed a desire to normalize assisted conception through disclosure and felt as though secrecy conflicted with this effort. Overall, disclosure was important to simply open-up the conversation about something that is not widely accepted and seemingly taboo. From a symbolic interactionist perspective, I suggest that disclosure was a response to parents' perception and experience of the social stigma associated with nonnormative childbearing techniques. I term this type of disclosure as subversive disclosure since the intention is to destabilize the stigma associated with nontraditional forms of reproduction. Differences in the importance of disclosure based on sexual identity was most salient when parents discussed their desire to have open and honest relationships. Otherwise

parents felt similarly about the significance of conception disclosure to children irrespective of their sexual identity.

In chapter 4, I highlighted that some participants experience the fertility treatment process as impersonal, regimented, and inflexible. While in chapter 6, however, I discussed that some participants used positive frames such as amazing to describe the technology. On the surface, it appears that there is a tension between these views, however, I argue that women are inspired to speak positively about the technology because the treatment was successful. Women appreciated the technology that allowed them to meet their objective of having a child, but this did not necessarily erase negative treatment experiences. Instead, such experiences made the journey worthwhile and became an important aspect of the child's conception story. Women's experience within the medical encounter is from their perspective as a patient while their post treatment/childbirth account is from the viewpoint of a parent. Additionally, the fertility treatment process should be viewed as an extension of the medicalization of pregnancy and childbirth. During pregnancy, women have repeated doctor's visits; undergo several tests and examinations; are typically expected to follow doctors' orders and recommendations; and often experienced several symptoms among them fatigue, nausea, cramping and headaches – some of which may persist for the entire pregnancy. At the end of a pregnancy however, the joys of giving birth to a child often overshadowed many, if not all, negative experiences including the pain associated with childbirth.

In Chapter 7, I identify and discuss some of the strategies parents employed in disclosing conception information to their children. In the past, professional advice was mixed about whether parents should disclose and how to do so. In my study, I find parents have been resourceful in their disclosure practice, often piecing together what they have learnt from print

sources and television as well relying on their own instinctual drive and abilities. Some parents disclosed early, as soon as the child was born or within the first few years of life while others took advantage of any opportunity they were presented with over the course of the child's life. According to Gamson (2015), who drew from the work of sociologists Ewick and Silbey,

> *"…narratives are told 'for a variety of reasons, to a variety of audiences, with a variety of effects,' and 'with particular interests, motives, and purposes in mind,' as 'narrators tell tales in order to achieve some goal or advance some interest.' Sometimes the interest is overt and conscious, and much of the time it is not. Still storytelling is always strategic" (p.205).*

When it came to conception disclosure approach, some parents spoke frankly about the treatment process and the persons involved while others came up with more creative ways of disclosing to include songs. In the telling of the conception story, parents also employed a hybrid approach combining timing decisions and strategic approaches. Irrespective of how disclosure happened and when, most parents were devoted to the process.

Based on communication privacy management theory, I expected parents to be engaged in disclosure that included established rules about confidentiality. However, I found that parents were less focused on what children would do with the information once they were told. I suggest, therefore, that family communication theories need to pay some attention to information sharing with respect to sensitive matters and theorize this as different from the management of private or confidential information.

Sexual minority women did not differ from heterosexual identified women with respect to their approach to disclosure. However, the data shows that for sexual minority women the content of their conception disclosure focused on different family structures and the many ways

families are built. For lesbian and gay persons, conception disclosure is not simply about the technique used to achieve pregnancy, it often requires folding in some details about their sexual identity and potentially the involvement of a third-party donor.

II. POST RESEARCH REFLECTION

Doing social research in general is a complex and intricate process. In this section I reflect on the methodological approach for my dissertation project, several lessons learnt and relevant points to note from my experience. My reflection spans across several areas of my research from questionnaire development through research termination.

ETHICAL CONCERNS

Since the data collection instrument was self-administered, I had no control over the respondent's environment. For individuals who seek medical assistance due to infertility issues, as well as for individuals who have endured the process with some prolonged physical, psychological and emotional stress, participating in the survey might cause the reemergence of some emotional stress or trauma. To help minimize the impact, contact information for support group services, was provided on the cover page from RESOLVE: The National Infertility Association and the GLBT National Help Center. An advantage of online surveys, however, is that they allow the respondent to determine when, where and at what time to complete the survey based on their assessment of the level of privacy needed and their emotional state. This could minimize the negative emotional effect of completing the survey.

PARTICIPANT RECRUITMENT

The ethics of joining private online groups for recruiting research participants must be considered. Several online communities are private and have established community etiquette and protocols which sometimes require that one must be a member to post. To become a member

sometimes requires emailing a request to the web administrator, whereas some pages have specific guidelines for persons who would like to publish a call for participants (CFP). Klein et al. (2010) suggest that among the things to consider when doing research online is that many websites have specific protocols about posting and member interaction. Among the rules of conduct is an option for members to file complaints, which could result in the researcher's email being blocked and barred from further registration (Klein et al. 2010:385). The authors suggest that the most ethical approach is to obtain approval from the website administrator prior to posting research recruitment information. Studies suggest that the recruitment of participant in these closed forums and support groups is sometimes frowned upon. Members of online communities may find such requests invasive given that much of the information shared is private and assumed accessible only to participants who have similar experiences. According to Catterall and Maclaran (2002) requests to assist with research are usually unwelcomed in online communities and can result in either "flaming," that is inflammatory responses, the message being ignored and even disengagement among members themselves (p.231). Robinson (2015) similarly experienced some difficulty recruiting participants from a website for persons who identify as gay for a study on race and online interaction. His profile was flagged as spam, blocked repeatedly and his IP address was eventually barred.

Participants for my research were recruited using several methods as outlined in earlier sections. Email listservs and friendship networks were by far the most accessible and most utilized resources. To be clear, persons who participated in the survey were never asked to indicate how they learned about the survey. However, I strategically rolled out recruitment strategies at different time periods, which allowed me to observe spikes in the participation rates overtime. The earlier period after the launch of the survey, as well as intermittent periods of email listserv blasts, resulted

in most traffic. The vast number of online forums, blogs, support groups and discussion boards did not yield as many bites as expected. For the purposes of my research, I contacted several web administrators to request permission to either have the CFP posted on their webpage or to become a member of the community to be able to do so. I received approval from one to sign up as a member and to further post the call to a discussion board specifically for persons who had conceived using ART. After a few days, I observed that the CFP was viewed by a significant number of members however, there was no noticeable difference in the traffic on the survey platform after the post was made. As noted earlier, the online presence of infertility support groups helped boost my confidence that an online survey was the most appropriate method of data collection. However, this endeavor was less successful than anticipated in recruiting participants. In response, I extended the length of time the survey was available to increase survey participation. The survey was initially intended to remain open for six months, but was extended twice and remained open for a total additional 5 month.

ATTRITION & PARTICIPANT FATIGUE

A total of 186 persons visited the survey, however they did not all complete the questionnaire. For a survey to be recorded as completed it must be submitted by the participant or closed out at the survey period. As noted on the survey cover page, participation in the survey was entirely voluntary and persons could refuse to answer questions or terminate the survey at any point. I used data on the last survey question answered by respondents to determine survey drop outs. A total of 22 participants exited the survey at the Q11 which asks, "What is your current gender identity?" This represents approximately 12% of the total 186 persons who entered the survey platform. As discussed in almost every research methodology text, questionnaire design is crucial to the validity, reliability and success of the survey. More specifically the placement of

questions considered intimate, sensitive, those vital to the research, and those of marginal importance is crucial. Questions about sexual orientation and gender identity might be considered sensitive questions for many and it might even be repulsive to a few. More recently however surveys have begun to include questions to allow for the determination of LGBT parent headed households (Russell & Muraco 2013). For the purposes of my research, sexual and gender identity were critical to main research objectives and so included in the first section despite concerns that it might be potentially disconcerting to some participants.

Persons terminated the survey at different points for various reasons. Another 10 participants were lost at Q38 "How many of those pregnancies resulted from the use of medical assistance?" As a reminder, the survey design also filtered participants to the end of the survey if their response to this question was equal to 0. Approximately 42% of the traffic to the survey submitted their response in the section on *Closing out: Demographics* at Q73 "What is your religious preference?" and another 18% at Q75 "Please share anything else you would like to about your overall experience seeking medical assistance to conceive and using assisted reproductive technologies." Overall, based on my review of item non-responses, individual surveys were at most 90% filled-in. Participant fatigue did not pose a concern during the pretesting of the instrument. However, it is noteworthy that a significant proportion of persons submitted their surveys before completing these final questions. Demographic questions were added at the end of the survey for this very same reason: in the event of participant fatigued, lost interest and/or did not have time.

RESTRICTING THE SAMPLE

The survey was restricted to the target population on two primary bases: 1) individuals who had used ART and 2) gave birth to at least one child as a result of ART. Restricting the sample presented minimally two advantages. Firstly, it simplified the call for participants to make it easier

for potential participants to determine if the request was applicable to them or not. Secondly, it streamlined the survey and made navigating the survey less complicated; once participants entered the survey, they would be able to complete the entire survey since almost all sections and questions would be applicable to them. The expected result is that the sample size would remain (more or less) stable across survey questions. It is necessary to note, however, that there is still no guarantee that making the call for participants as specific as possible would eliminate participation of persons for whom the research was not intended. It is still important to include filter questions to determine that the individuals who participate do in fact meet the criteria. The survey question - *How many of those pregnancies resulted from the use of medical assistance?* was a filter question, which allowed individuals to be filtered out of the survey if their answer was equal to 0. Additionally, I received emails seeking eligibility clarification and from persons with a strong desire to share their story, but who were pregnant at the time and so did not meet the second criteria for participation.

Restricting a sample to such a particular group is not without its challenges. As previously discussed in Chapter two, assisted reproduction is only accessible to a small proportion of persons and there is even a smaller proportion of persons who exhibit help-seeking behaviors. This is due to various factors, among them state laws, insurance policies, social stigma, and costs. Consequently, the socio-economic characteristics for this group showed very little variation. Due to the nature of medically assisted conception, participants shared very similar characteristics. Restricting the sample based on the two named criteria therefore resulted in the homogenization of the sample. For this reason, analyses which seek to examine differences based on certain socio-demographic factors are either limited or impossible. However, considering that the focus of my research was an examination of attitudes about disclosure and disclosure behavior among ART users, the decision to restrict the sample was justified by the advantages of this approach.

III. OPPORTUNITIES FOR FUTURE RESEARCH

My research and analysis offers some insight on the experience of assisted conception and some pertinent decisions and choices concerning conception disclosure. Most importantly, I have highlighted differences and similarities in these experiences based on sexual identity. Notwithstanding, there are some questions that arise from my research that future research should attend to. I outline a few of these opportunities for future research in this section.

Based on the narrative presented by participants pertaining to the experience of fertility treatment, some parents were enchanted by the fruitful outcome of the assisted reproductive technologies and spoke positively about them. In light of some feminist concerns, questions remain: Is the more revered framing of ART a growing perspective? How does this perspective on ART feed into a contemporary feminist perspective on ART?

In my research, I explore disclosure from the perspective of the birthing mother. However, conception disclosure is not necessarily her sole decision. Other persons are sometimes involved both in the decision-making process and the execution of disclosure. Further research should therefore explore: who are the persons involved in the conception disclosure decision-making process; what are the areas of consensus and disagreement; and where disagreements existed, how those were resolved. Research in this area would also be helpful in broadening communication theory concerning joint ownership and management of conception information.

In my analysis, I have also discussed the influence of social norms and more specifically, stigma in decisions about conception disclosure. Future studies should therefore attempt to more systematically examine stigma experience and responses to such experience among ART users. It is unclear from my data whether the references to stigma were about conception with medical technologies, whether they were specifically associated with the infertility experience, the use of

gamete donation, or a combination of these. Future studies should therefore attempt to break through these complexities to examine disclosure practice per the participants' view of specific discredited status.

From a methodological standpoint, some data presented in my research are based on questions about future behaviors. I, therefore, suggest that longitudinal studies should examine differences, for example, between intended and actual disclosure behaviors. Additionally, in this research, I have developed two scales, future research based on a larger sample is necessary to assist with validating both my fear motivated non-disclosure and care motivated disclosure scales.

Conception disclosure is a complex issue that will continue to dominate sociological research especially considering the continued advancement of reproductive science. Along this line, implications for future research include: establishing how individuals make decisions about who to share the information with and how much to share; determining the true effect of infertility status on conception disclosure using larger probability samples; qualitatively exploring the role of sexuality in disclosure decisions; and determining the impact of disclosure on individual social life such as interpersonal relationships.

IV. A FINAL NOTE

Medical sociologists have examined power relations in the medical encounter for years and several others have discussed the medicalization of infertility and assisted technologies as tools intended to enhance physician authority. Yet, a sociological analysis of the fertility treatment experience remains both critical and timely. With the increase in the proportion of persons accessing assisted reproductive technologies, the barriers to access ART for groups of persons, and the continued advancement in the area, medical sociology and a sociology of reproduction demands our attention to emergent and persistent issues. What is evident from the

data presented in my dissertation is that medicine is still an institution of social control and that physicians still hold significant power. Notwithstanding, patients are not simply passive, powerless, or docile. Increasing access to information and support networks has contributed to a more aware and empowered medical consumer, who now have a voice and uses that voice to influence medical authority.

Disclosure of ART user status is sociologically important. According to Loe (2004), sociology has been long concerned with "how individuals internalize society's norms; how normality and abnormality are defined, and by whom; how and why particular social groups and individuals are sanctioned for being different from the norm; how social norms shift in relation to historical, economic, political, and cultural change; and how social norms reflect and perpetuate social inequalities" (p.19). Disclosure about the use of ART is therefore of sociological significance because it takes into consideration how becoming parents is historically and socially constructed as normal based on heterosexuality, conjugal sexual relations, and genetic kinship. The use of words such as *artificial* in artificial insemination and the distinction between natural reproduction as opposed to *medically assisted conception* does a significant amount of work in establishing what is normal and what is unconventional in the realm of procreation. If pregnancy assumes heterosexual practice and relationship, and thus signifies one as normal, the disclosure of one's ART status therefore marks one as somehow different. Based on my study, parents are engaged in a process of dismantling these beliefs, establishing assisted conception as one of many ways to conceive a child, and depicting it in a positive manner. Silence symbolizes shame while disclosure establishes ART as one of many ways to build family.

APPENDICES

Survey Cover Page

SYRACUSE UNIVERSITY
MAXWELL SCHOOL OF CITIZENSHIP AND PUBLIC AFFAIRS
College of Arts &Sciences / Department of Sociology

Dear Participant,

Have you achieved pregnancy through the use of reproductive technologies? If yes, you are invited to participate in this study on medically assisted reproduction, which is a dissertation project aimed at understanding the experience of, and attitude towards telling others about, the use of reproductive technologies. The survey is estimated to take between 30-45 minutes to complete and includes questions about your desire to become a parent, your experience seeking medical assistance to conceive, your experience with pregnancy, level of support from family and friends, and how you decide to share your experience with others.

This survey is for individuals 18 years and older, living in the United States who have used reproductive technologies as a pathway to childbearing. To be eligible, you must have given birth to a child conceived with medical assistance. If you self-identify with any of these populations, then I would like to invite you to participate in this study.

Your participation in this study is completely voluntary. There is minimal risk involved in this research, however, should you experience any discomfort you can refuse to answer any survey question(s) and/or withdraw from the survey at any time without consequence. Although unlikely, should you experience undue stress during this survey, please stop and call the RESOLVE helpline (numbers are listed by regions at: http://www.resolve.org/support/helpline.html) or the GLBT National Help Center Hotline (1-888-843-4564) for free and confidential support and other available resources.

Whenever one works with email or the internet; there is always the risk of compromising privacy, confidentiality, and/or anonymity. Your confidentiality will be maintained to the degree permitted by the technology being used. It is important for you to understand that no guarantees can be made regarding the interception of data sent via the internet by third parties.

For any questions, please contact the researcher Natalee Simpson (nmsimpso@syr.edu) or her project adviser Janet Wilmoth (jwilmoth@maxwell.syr.edu or 315-443-5053). If you have questions or concerns about your rights as a research participant, you can call the Syracuse University Office of Research and Integrity Protections by phone at (315) 443-3013. This research project has been approved by the Syracuse University IRB (reference # 14-344).

By clicking NEXT you consent to participate and to being 18 years and older. Please feel free to save a copy of this page for your records and to also share, invite and refer others to the survey.

I sincerely appreciate the time that you have taken as well as your participation.

Natalee Simpson
PhD Candidate
Department of Sociology
Syracuse University
302 Maxwell Hall
Syracuse, New York 13244

Q2 How old are you?

Q3 With which one of the following race categories do you most identify?
- ❍ American Indian or Alaska Native (1)
- ❍ Asian (2)
- ❍ Black or African American (3)
- ❍ Native Hawaiian or Other Pacific Island (4)
- ❍ White (5)
- ❍ Bi-racial (6)
- ❍ Mixed (7)
- ❍ Other (8) _____

Q4 Are you Hispanic or Latino?
- ❍ Yes (1)
- ❍ No (2)

Q5 What is your relationship status?
- ❍ Married (1)
- ❍ Divorced (2)
- ❍ Widowed (3)
- ❍ Separated (4)
- ❍ Cohabiting (5)
- ❍ Single/never married (6)

Q6 In which state do you currently reside?

- ❍ Alabama (1)
- ❍ Alaska (2)
- ❍ Arizona (3)
- ❍ Arkansas (4)
- ❍ California (5)
- ❍ Colorado (6)
- ❍ Connecticut (7)
- ❍ Delaware (8)
- ❍ District of Columbia (9)
- ❍ Florida (10)
- ❍ Georgia (11)
- ❍ Hawaii (12)
- ❍ Idaho (13)
- ❍ Illinois (14)
- ❍ Indiana (15)
- ❍ Iowa (16)
- ❍ Kansas (17)
- ❍ Kentucky (18)
- ❍ Louisiana (19)
- ❍ Maine (20)
- ❍ Maryland (21)
- ❍ Massachusetts (22)
- ❍ Michigan (23)
- ❍ Minnesota (24)
- ❍ Mississippi (25)
- ❍ Missouri (26)
- ❍ Montana (27)
- ❍ Nebraska (28)
- ❍ Nevada (29)
- ❍ New Hampshire (30)
- ❍ New Jersey (31)
- ❍ New Mexico (32)
- ❍ New York (33)
- ❍ North Carolina (34)
- ❍ North Dakota (35)
- ❍ Ohio (36)
- ❍ Oklahoma (37)
- ❍ Oregon (38)
- ❍ Pennsylvania (39)
- ❍ Puerto Rico (40)
- ❍ Rhode Island (41)
- ❍ South Carolina (42)
- ❍ South Dakota (43)

- ❍ Tennessee (44)
- ❍ Texas (45)
- ❍ Utah (46)
- ❍ Vermont (47)
- ❍ Virginia (48)
- ❍ Washington (49)
- ❍ West Virginia (50)
- ❍ Wisconsin (51)
- ❍ Wyoming (52)
- ❍ I do not reside in the United States (53)

Q7 What is the highest degree or level of school you have completed? Mark ONE box. If you are currently enrolled, please mark the previous grade or highest.

- ❍ Elementary and/or junior high (1)
- ❍ Some high school to 12th grade (2)
- ❍ High school graduate - high school Diploma or the equivalent (3)
- ❍ Technical school degree (4)
- ❍ Associate degree (5)
- ❍ Bachelor's degree (6)
- ❍ Master's degree (7)
- ❍ Professional degree (e.g. Lawyer, Medical Doctor, Architect) (8)
- ❍ Doctorate degree (9)

Q8 What is your employment status?

- ❍ Employed Full-time (1)
- ❍ Employed Part-time (2)
- ❍ Unemployed (3)
- ❍ Retired (4)
- ❍ Student (5)
- ❍ Disabled (6)
- ❍ Other (7) _____

Q9 What is your sex assigned at birth?

- ❍ Male (1)
- ❍ Female (2)

Q10 Which of the following best describes you?
- ❍ Heterosexual (1)
- ❍ Lesbian (2)
- ❍ Gay (3)
- ❍ Bisexual (4)
- ❍ Unsure (5)
- ❍ Other (6) _____

Q11 What is your current gender identity?
- ❍ Male/Man (1)
- ❍ Female/Woman (2)
- ❍ Female-to-Male (FTM)/Transgender Male/Trans Man (3)
- ❍ Male-to-Female (MTF)/Transgender Female/Trans Woman (4)
- ❍ Genderqueer/Gender non-conforming (5)
- ❍ Other (6) _____

Q12 Please indicate the level of importance you placed on each of the items below as it related to your motivations to become a parent. Before I had children, it was important to me to become a parent because…

	Very Important (1)	Important (2)	Somewhat Important (3)	Not Important (4)
It is nice to have children around (1)	❍	❍	❍	❍
Parenting fulfills motherly/fatherly feelings (2)	❍	❍	❍	❍
Being a parent makes the relationship with your partner complete (3)	❍	❍	❍	❍
It is obvious to have children (4)	❍	❍	❍	❍
It will continue the family name/tradition (5)	❍	❍	❍	❍
Parenthood is satisfying (6)	❍	❍	❍	❍
I don't want to be alone when I am old (7)	❍	❍	❍	❍
Children make life complete (8)	❍	❍	❍	❍
My environment (others, family) expect it of me (9)	❍	❍	❍	❍
I want to have unique relationship with the child (10)	❍	❍	❍	❍
I want to experience pregnancy and birth (11)	❍	❍	❍	❍
Bringing up children brings happiness (12)	❍	❍	❍	❍
Being a parent	❍	❍	❍	❍

gives me a goal to live for (13)				
Being a parent is a sign of being grown up (14)	❍	❍	❍	❍
I want to have something of myself continue living after I'm dead (15)	❍	❍	❍	❍
Becoming a parent is the nature of man/woman (16)	❍	❍	❍	❍
Others around me have children (17)	❍	❍	❍	❍
I want to avoid being an outsider (18)	❍	❍	❍	❍

Q13 At some time in the future, would you like to have another child?

❍ Yes (1)

❍ No (2)

❍ Unsure (3)

Q14 At the time you first sought medical assistance to become pregnant, was it you or your partner who wanted to have a baby?

- ❍ Self (1)
- ❍ Partner (2)
- ❍ Both (3)

Q15 At the time you first sought medical assistance to become pregnant, did you already have a child (biological, adopted, foster or step child)?

- ❍ Yes (1)
- ❍ No (2)

Q16 At the time you first sought medical assistance to become pregnant, how old were you?

Q17 What kind of medical assistance have you used to get pregnant? (Check all that apply)

- ❑ Intra-uterine Insemination (IUI) (1)
- ❑ In-vitro Fertilization (IVF) (2)
- ❑ Gamete Intrafallopian Transfer (GIFT) (3)
- ❑ Zygote Intrafallopian Transfer (ZIFT) (4)
- ❑ Artificial Insemination (5)
- ❑ Fertility Medication (6)
- ❑ Other (7) _____

Q18 During your successful medical procedure(s), did you use donor embryo or sperm?

	Yes (1)	No (2)
Donor Embryo (1)	❍	❍
Donor Sperm (2)	❍	❍

Q19 Do you currently have embryo in storage?
❍ Yes (1)
❍ No (2)

Q20 Was there ever a time when you were trying to get pregnant but did not conceive within 12 months?
❍ Yes (1)
❍ No (2)

Q21 Have you ever been diagnosed or treated for a medical condition that prevented you from having a child? (For e.g. Endometriosis, Pelvic inflammatory disease, Polycystic ovary syndrome etc.)
❍ Yes (1)
❍ No (2)

Q22 How long were you trying to become pregnant before starting medical treatment?
- ❍ Months (1) _____
- ❍ Weeks (2) _____
- ❍ Don't Know (3)
- ❍ Refused (4)
- ❍ Never Tried/Not Applicable (5)

Q23 In total how many medical treatment attempts have you had? (This question refers to actual medical procedures, for e.g. IUI, IVF etc. regardless of the outcome)

If In total how many medical t... Is Equal to 0, Then Skip To End of Survey

Q24 How long did it take from the time of your first medical procedure until you became pregnant?
- ❍ Months (1) _____
- ❍ Weeks (2) _____
- ❍ Don't Know (3)
- ❍ Refused (4)

Q25 Did your health insurance provide coverage for the medical procedure(s)?
- ❍ Yes (1)
- ❍ No (2)
- ❍ Uninsured (3)

Display This Question:
If Did your health insurance provide coverage for treatment? Yes Is Selected

Q26 Was your insurance benefit adequate in covering the costs associated with the medical procedures?
- ❍ Yes (1)
- ❍ No (2)

Display This Question:
If Did your health insurance provide coverage for the medical procedure(s)? No Is Selected
Or Did your health insurance provide coverage for the medical procedure(s)? Uninsured Is Selected
Or Was your insurance benefit adequate in covering the costs associated with the medical procedures? No Is Selected

Q27 How did you cover the (full or partial) cost of the medical procedure(s)? (Check all that apply.)
- ❑ Loan (1)
- ❑ Personal Funds (2)
- ❑ Other (3) _____

Q28 At the time you were trying to conceive, did you discuss getting pregnant with your:

	Yes (1)	No (2)	Not Applicable (3)
Spouse/Partner (1)	❍	❍	❍
Family (2)	❍	❍	❍
Friends (3)	❍	❍	❍
Others who have had treatment (4)	❍	❍	❍
Other (5)	❍	❍	❍

Q29 During the process of trying to get pregnant, how supportive was/were your:

	Very Supportive (1)	Somewhat Supportive (2)	Not At All Supportive (3)	Not Applicable (4)
Spouse/Partner (1)	❍	❍	❍	❍
Family (2)	❍	❍	❍	❍
Friends (3)	❍	❍	❍	❍
Others who have had treatment (4)	❍	❍	❍	❍
Other (5)	❍	❍	❍	❍

Q30 Did you attend a support group to help you cope during the process of trying to get pregnant?

❍ Yes (1)
❍ No (2)

Q31 Are you currently seeking medical assistance to become pregnant?

❍ Yes (1)
❍ No (2)

Q32 What advice would you give to other individuals seeking medical assistance to conceive? (NOTE: No character limit)

Q33 How many times have you been pregnant in your life? (Include all pregnancies regardless of outcome, regardless of whether it was with or without medical assistance and if currently pregnant)

If How many times have you bee... Is Equal to 0, Then Skip To End of Survey

Q34 Have any of those pregnancies ended in a spontaneous loss like a miscarriage or an ectopic pregnancy?

- ❍ Yes (1)
- ❍ No (2)

Display This Question:

If Have any of those pregnancies ended in a spontaneous loss like a miscarriage or an ectopic pregna... Yes Is Selected

Q35 How many spontaneous pregnancy losses have you had?

Q36 Have any of those pregnancies ended in the loss of a baby during labor, birth or in the early days after birth?

- ❍ Yes (1)
- ❍ No (2)

Display This Question:

If What about the loss of a baby during labor, birth or in the early days after birth? Yes Is Selected

Q37 How many?

Q38 How many of those pregnancies resulted from the use of medical assistance?

If How many of those pregnanci... Is Equal to 0, Then Skip To End of Survey

Q39 The next set of questions ask you to share some details about your encounter with medical professionals when you were specifically seeking fertility treatment, inclusive of doctors, nurses, clinic and clerical staff.

Q40 When you sought help were you…?

	Yes (1)	No (2)
Single (1)	❍	❍
Partnered with a female person (3)	❍	❍
Partnered with a male person (4)	❍	❍
Female-to-Male (FTM) Transgender Male/Trans Man (5)	❍	❍
Male-to-Female (MTF) Transgender Female/Trans Woman (6)	❍	❍
Genderqueer/Gender non-conforming (7)	❍	❍

Q41 Have you ever been to a fertility clinic to talk about ways to help you have a baby?

❍ Yes (1)
❍ No (2)

If No Is Selected, Then Skip To Have you ever made the decision to ch...

Q42 How did you learn about the fertility clinic that you sought services from? (Check all that apply.)

❑ Family (1)
❑ Friend (2)
❑ General Practitioner (3)
❑ OB/GYN (8)
❑ Fertility Specialist (9)
❑ Nurse (10)
❑ Magazine/Newspaper (4)
❑ Radio/Television (5)
❑ Internet (6)
❑ Other (7) _____

Q43 When deciding on a fertility clinic, how important were each of these factors?

	Very Important (1)	Somewhat Important (2)	Not At All Important (3)
Recommendation from family (1)	❍	❍	❍
Recommendation from friend (4)	❍	❍	❍
Recommendation from Physician/Medical Consultant (5)	❍	❍	❍
Treatment cost (2)	❍	❍	❍
Treatment success rate (3)	❍	❍	❍
Clinic's reputation (6)	❍	❍	❍
Clinic's distance from home (7)	❍	❍	❍
Clinic non-discrimination policy (8)	❍	❍	❍
Friendly & courteous clinic staff (9)	❍	❍	❍

Q44 When you were seeking treatment, were you ever refused fertility services from a clinic?
❍ Yes (1)
❍ No (2)

Display This Question:
If When you were seeking treatment, were you ever refused fertility services from a clinic? Yes Is Selected

Q45 Why were you refused? (NOTE: No character limit)

Q46 Have you ever made the decision to change fertility clinics?
❍ Yes (1)
❍ No (2)

Display This Question:
If Have you ever made the decision to change fertility clinics? Yes Is Selected

Q47 Why did you make the decision to change clinic? (NOTE: No character limit)

Q48 Have you ever made the decision to change fertility doctors?
- ❍ Yes (1)
- ❍ No (2)

Display This Question:
If Have you ever made the decision to change doctors? Yes Is Selected

Q49 Why did you make the decision to change doctor? (NOTE: No character limit)

Q50 During any of your pregnancies resulting from assisted reproductive technologies, did you ever visit a doctor or other medical personnel for prenatal care?
- ❍ Yes (1)
- ❍ No (2)

Display This Question:
If During any of your pregnancies resulting from assisted reproductive technologies, did you ever vi... Yes Is Selected

Q51 Please describe your overall experience during the period of prenatal care. (NOTE: No character limit)

Q52 Where did you give birth? Check all that apply. (This question speaks specifically to pregnancies resulting from the use of assisted reproductive technologies)
- ❑ Hospital (1)
- ❑ Birthing center (2)
- ❑ Home (3)
- ❑ Other (4) _____

Q53 Please describe your overall experience giving birth. (NOTE: No character limit)

Q54 How would you rate your overall experiences during the process of seeking medical assistance to achieve pregnancy:

	Poor (1)	Fair (2)	Good (3)	Excellent (4)	Not Applicable (5)
Doctors (1)	❍	❍	❍	❍	❍
Nurses (2)	❍	❍	❍	❍	❍
Clinic staff (3)	❍	❍	❍	❍	❍

Q55 Please describe your overall experience seeking medical assistance to achieve pregnancy. (NOTE: No character limit)

Q56 During your fertility treatment and medical encounter(s) while pregnant, have you ever felt discriminated against based on:

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	All the time (5)
Race (1)	❍	❍	❍	❍	❍
Sexuality (2)	❍	❍	❍	❍	❍
Economic status (3)	❍	❍	❍	❍	❍
Educational level (6)	❍	❍	❍	❍	❍
Citizenship (4)	❍	❍	❍	❍	❍
Language (5)	❍	❍	❍	❍	❍
Gender presentation (7)	❍	❍	❍	❍	❍
Age (8)	❍	❍	❍	❍	❍
Other (9)	❍	❍	❍	❍	❍

Q57 Thinking about your overall experiences seeking fertility treatment, please indicate your level of agreement with the following statement:

	Never (1)	Rarely (7)	Sometimes (2)	Most of the Time (3)	Always (4)	Not Applicable (5)
The clinic staff was very professional (1)	❍	❍	❍	❍	❍	❍
The physician was always willing to address concerns (7)	❍	❍	❍	❍	❍	❍
The physician cared about my well being (8)	❍	❍	❍	❍	❍	❍
I felt satisfied with the services provided by the clinic staff (9)	❍	❍	❍	❍	❍	❍
I did not feel included in determining the treatment plan (10)	❍	❍	❍	❍	❍	❍
The clinic staff was usually respectful (11)	❍	❍	❍	❍	❍	❍
The physician provided information about treatment procedures (12)	❍	❍	❍	❍	❍	❍
I did not feel emotionally supported by the clinic staff (13)	❍	❍	❍	❍	❍	❍
I felt comfortable with the services received at the hospital/birthing center (14)	❍	❍	❍	❍	❍	❍

I felt that we could call the physician if we needed anything (15)	❍	❍	❍	❍	❍	❍
The physician was always willing to listen to my/our concerns (16)	❍	❍	❍	❍	❍	❍
I did not feel encouraged to ask questions during consultations (17)	❍	❍	❍	❍	❍	❍
The physician was always very friendly (18)	❍	❍	❍	❍	❍	❍
I felt pressured by the physician to choose specific methods (19)	❍	❍	❍	❍	❍	❍

Q58 How many people know that your child(ren) was (were) conceived with medical assistance?

	None (1)	Some (2)	Quite a Bit (3)	An Extreme Amount (4)	All (5)	Not Applicable (6)
Family (1)	❍	❍	❍	❍	❍	❍
Close Friends (6)	❍	❍	❍	❍	❍	❍
Casual Friends/Acquaintances (7)	❍	❍	❍	❍	❍	❍
Work colleagues (2)	❍	❍	❍	❍	❍	❍
Children's school/Nursery (3)	❍	❍	❍	❍	❍	❍
Social groups/community (4)	❍	❍	❍	❍	❍	❍

Q59 Have you informed your family doctor that your child(ren) was(were) conceived with medical assistance?
- ❍ Yes (1)
- ❍ No (2)

Q60 Have you disclosed to your child(ren) about how they were conceived?
- ❍ Yes (1)
- ❍ No (2)

If Yes Is Selected, Then Skip To How important is it to share informat...

Display This Question:
If Have you disclosed to your child(ren) about how they were conceived? Yes Is Selected

Q61 Please describe your experience disclosing to your child(ren) about how they were conceived. (NOTE: No character limit)

Q62 Do you intend to disclose to your child(ren) about how they were conceived?
- ❍ Yes (1)
- ❍ No (2)
- ❍ Unsure (3)

Q63 How important is it to share information with your child(ren) about their conception?
- ❍ Not important (1)
- ❍ Somewhat important (2)
- ❍ Very Important (3)

Q64 Please share more about why you think it is important, somewhat or not important? (NOTE: No character limit)

Display This Question:
If Have you disclosed to your child(ren) about how they were conceived? Yes Is Selected
Or Do you intend to disclose to your child(ren) about how they were conceived? Yes Is Selected

Q65 How did you, or how do you plan to disclose information about conception to your child(ren)? (NOTE: No character limit)

Q66 Were you given advice by any of the following persons about how to disclose to your children(s), family or friends that you used medical assistance to conceive ?

	Yes (1)	No (2)	Not Applicable (3)
Physician/Consultant (1)	❍	❍	❍
Nurses (3)	❍	❍	❍
Psychiatrist/Counselor (4)	❍	❍	❍
Clinic Director (5)	❍	❍	❍
Other (2)	❍	❍	❍

Q67 GENERAL ATTITUDES TOWARDS DISCLOSURE ABOUT THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY TO CONCEIVE

	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Agree (5)
Children have a right to know how they were conceived (1)	❍	❍	❍	❍	❍
Health-care professionals should be informed of patients conception history (6)	❍	❍	❍	❍	❍
Disclosure is more difficult when there is a donor involved (7)	❍	❍	❍	❍	❍
Nondisclosure is the best way to avoid shame and stigma (2)	❍	❍	❍	❍	❍
One will know when the time is right to disclose (8)	❍	❍	❍	❍	❍
Families treat children poorly when they know the child was not conceived naturally (9)	❍	❍	❍	❍	❍
Disclosure threatens children's sense of identity (10)	❍	❍	❍	❍	❍
Disclosure leads to stigmatization (11)	❍	❍	❍	❍	❍

Having a support network makes disclosure less painful (12)	❍	❍	❍	❍	❍
Disclosure is the best way to protect the child from accidental discovery (13)	❍	❍	❍	❍	❍
Nondisclosure is the best way to protect the child (14)	❍	❍	❍	❍	❍
People are generally judgmental towards individuals who use medical assistance to conceive (15)	❍	❍	❍	❍	❍
The use of reproductive technology is a private matter (16)	❍	❍	❍	❍	❍
Parents should wait for the child to ask (3)	❍	❍	❍	❍	❍
Disclosure will negatively impact the parent-child relationship (4)	❍	❍	❍	❍	❍
Parents and children are 'co-owners' of their conception story (17)	❍	❍	❍	❍	❍
Health	❍	❍	❍	❍	❍

practitioners should be required to provide resources to assist with disclosure (18)					
Disclosure is a way to demonstrate to the child how much they are wanted (19)	❍	❍	❍	❍	❍

Q68 Please share anything else you would like about your experience while seeking treatment and the process of using assisted reproductive technologies. (NOTE: No character limit)

Q69 What is the sex of your current partner(s)?
- ❍ Male (1)
- ❍ Female (2)
- ❍ Both (3)

Q70 What is your (primary) partner's current gender identity?
- ❍ Male/Man (1)
- ❍ Female/Woman (2)
- ❍ Female-to-Male (FTM)/Transgender Male/Trans Man (3)
- ❍ Male-to-Female (MTF)/Transgender Female/Trans Woman (4)
- ❍ Genderqueer/Gender non-conforming (5)
- ❍ Other (6) _____

Q71 How many children do you have? (Include also adopted, foster and step children)

Q72 What is your current personal gross annual income (before taxes)?
- ❍ Less than $19,000 (1)
- ❍ $20,000 to $39,999 (2)
- ❍ $40,000 to $59,999 (3)
- ❍ $60,000 to $79,999 (4)
- ❍ $80,000 to $99,999 (5)
- ❍ $100,000 to $149,999 (6)
- ❍ $150,000 to $ 199,999 (7)
- ❍ More than $200,000 (8)

Q73 What is your religious preference?
- ❍ None (1)
- ❍ Protestant (2)
- ❍ Catholic (3)
- ❍ Jewish (4)
- ❍ Mormon (5)
- ❍ Muslim (6)
- ❍ Buddhist (7)
- ❍ Hindu (8)
- ❍ Jehovah's witness (9)
- ❍ Other (10) _____

Q74 How often do you usually attend religious services?
- ❍ Never (1)
- ❍ Less than Once a Month (2)
- ❍ Once a Month (3)
- ❍ 2-3 Times a Month (4)
- ❍ Once a Week (5)
- ❍ 2-3 Times a Week (6)
- ❍ Daily (7)

Q75 Please share anything else you would like to about your overall experience seeking medical assistance to conceive and using assisted reproductive technologies. (NOTE: No character limit)

APPENDIX B: SUMMARY PRETEST FEEDBACK

The pretest was conducted over the period February 11-22, 2015. Five participants who met the eligibility criteria for the survey were asked to complete, evaluate and report their experience. The primary goal was to determine whether the questionnaire and other related implementation procedures such as the technology and survey tool, were adequate for an extended study. Pretest participants were recruited through friendship and family networks.

Major objectives were to determine:

1. If questions were clearly written;
2. If response options were exhaustive and mutually exclusive;
3. If questions evoked feeling of unease or discomfort;
4. Average completion and an assessment of survey length;
5. If skip and display logic were necessary;
6. If skip and display logic embedded in the survey worked;
7. If the survey questions flowed well;
8. If the look and feel of the survey was appropriate;
9. Non-response and variation on certain questions;
10. If survey hyperlink access was fully functional.

GENERAL COMMENTS & CONCERNS:

Overall, participants reported that the survey flowed well, that the questions were clear and did not provoke any feelings of discomfort. In response to the question about the length of the survey, respondents felt the length of the survey was just about right.

Participants had two main concerns:

- Memory recall due to the length of time that had elapsed between the experiences and taking the survey.
- At least one felt the survey did not allow her to provide details of her story. Two participants included an extended story of their experience in email.

COMMENTS ON SPECIFIC QUESTIONS:

- **Highest degree of level of school completed**

  Clarification required on what is a "professional degree". Suggestion to add examples.

- **Parenthood Motivations**

  Difficult to quantify with just "agree" and/or "somewhat agree."

- **If Artificial Insemination, was it with donor embryo or sperm?**

  Requires a display logic

- **Total medical attempts (referring to actual medical procedures)**

Wasn't exactly sure whether this included failed attempts, successful attempts, or both.

- **Length of time from first medical treatment to conception**

  Clarification required about how long from very first treatment (of any kind) to conception?

  Response options does not include years

- **Insurance coverage**

  Limited options for yes, no or uninsured. (Note that insurance covered office visits and some drugs but *not IVF).*

- **Discuss getting pregnant with others**

  Could use a “Not Applicable”

- **How did respondent learn about fertility clinic**

  Include OB.GYN, fertility specialist, nurses

- **Important factors when deciding on fertility clinic**

  Include “Prestige”

- **Describe overall experience – Prenatal care, giving birth, seeking medical assistance**

  Set of questions asking to "Describe your overall experience." Needs to be more specific about which experience - fertility center, OB/GYN, hospital, etc.

- **Level of agreement with set of questions about experiences seeking fertility treatment**

  Question should be specific about which physician - the fertility clinic doctor, OB/GYN, doctors in the hospital, family doctor, pediatrician etc

- **How many people know child was conceived with medical assistance?**

  Could use a “Not Applicable”

- **Disclosure to child(ren)**

  Needs a third option - "Not yet."

- **Advice about disclosure**

  Could use a “Not Applicable”

- **Attitudes towards disclosure**

  Clarification whether this pertains to own situation or in general

SUGGESTED QUESTIONS:

- Whether someone had children before trying to conceive again (primary or secondary infertility).
- Whether the child(ren) conceived through ART occurred within a second marriage.
- Maternal age at conception? (of naturally born and “artificially conceived children”).
- A general question about how the child(ren) were conceived, beyond the basic "method" question (IUI, IVF, etc.).
- Include question about the experience of finding a pediatrician.

OTHER QUESTIONS AND COMMENTS

- Why not including women who tried reproductive technologies but did not get pregnant?

SURVEY MODIFICATIONS:

General changes made to the survey post pretest included:

- Adding “Not Applicable” as a response option;
- Adding response options to a few questions based on suggestions;
- Adding and clarifying questions;
- Include clarifying statements where needed;
- Adding skip patterns;
- Inserting an additional open ended question to allow participants to provide more details;
- Include a note that open ended questions had no character limit.

PREGNANCY ACHIEVED THROUGH ASSISTED REPRODUCTIVE TECHNOLOGY (ART)

Have you achieved pregnancy through the use of reproductive technologies?
If yes, you are invited to participate in this dissertation project aimed at understanding your experiences. The survey is estimated to take 30 minutes to complete.

To be eligible, you must:

- ✓ Be 18 years or older,
- ✓ Live in the United States,
- ✓ Have given birth to a child conceived with the use of ART.

To participate in the survey, please use a smart phone to scan the QR Code.

Open QR Code reader from a smartphone. Hold the device over the QR Code until visible on the screen of the phone. The code will either scan automatically or with the press of a button similar to taking a photo.

OR

type the following in a webpage browser:
https://syracuseuniversity.qualtrics.com/SE/?SID=SV_daHoHfRCfqBw1Lf

For any questions, please contact the researcher Natalee Simpson (nmsimpso@syr.edu) or her project adviser Janet Wilmoth (jwilmoth@maxwell.syr.edu or 315-443-5053).

This research project has been approved by the Syracuse University Institutional Review Board (reference # 14-344).

THANK YOU IN ADVANCE FOR YOUR PARTICIPATION!

SYRACUSE UNIVERSITY
Institutional Review Board
MEMORANDUM

TO: Janet Wilmoth
DATE: December 10, 2014
SUBJECT: **Submitted for Expedited Review-Determination of Exemption from Regulations Modifications Required**
IRB #: 14-344
TITLE: *Families Designed Through Assisted Reproductive Technologies (ART)*

The above referenced application, submitted for expedited review has been determined by the Institutional Review Board (IRB) to be exempt from federal regulations as defined in 45 C.F.R. 46, and has been evaluated for the following:

1. determination that it falls within the one or more of the five exempt categories allowed by the organization;
2. determination that the research meets the organization's ethical standards.

It has been determined by the IRB that authorization of your protocol is deferred until you respond to the modifications required or issues raised below:

1. **In Section 8.1, if the administrators of the sources you have listed will provide you with listservs or private contact information of potential participants then you must name/list these groups, and provide letters of cooperation from each group/forum/blog, etc.**

Note: Electronic submission via e-mail: orip@syr.edu or fax: (315) 443.9889 is acceptable.

These required modifications should be addressed in a memorandum outlining changes; including highlighted changes to the application. Make sure to reference your IRB # on all communications. All correspondence should be sent to the address below within **ONE MONTH** of the date of this letter.

As a reminder, you may not initiate this human participants research project until the protocol receives IRB authorization.

Thank you for your cooperation in our shared efforts to assure that the rights and welfare of people participating in research are protected.

Tracy Cromp, M.S.W.
Director

DEPT: Sociology, 314 Lyman Hall **STUDENT:** Natalee Simpson

Office of Research Integrity and Protections
121 Bowne Hall Syracuse, New York 13244-1200
(Phone) 315.443.3013 ♦ (Fax) 315.443.9889
orip@syr.edu ♦ www.orip.syr.edu

SYRACUSE UNIVERSITY
Institutional Review Board
MEMORANDUM

TO: Janet Wilmoth
DATE: December 4, 2015
SUBJECT: **Amendment for Exempt Protocol**
AMENDMENT#: 1 – Change in Recruitment Materials/Methods (Flyer)
IRB #: 14-344
TITLE: *Families Designed Through Assisted Reproductive Technologies (ART)*

Your current exempt protocol has been re-evaluated by the Institutional Review Board (IRB) with the inclusion of the above referenced amendment. Based on the information you have provided, this amendment is authorized and continues to be assigned to category **2**. This protocol remains in effect from **December 19, 2014** to **December 18, 2019**.

CHANGES TO PROTOCOL: Proposed changes to this protocol during the period for which IRB authorization has already been given, cannot be initiated without additional IRB review. If there is a change in your research, you should notify the IRB immediately to determine whether your research protocol continues to qualify for exemption or if submission of an expedited or full board IRB protocol is required. Information about the University's human participants protection program can be found at: http://orip.syr.edu/human-research/human-research-irb.html Protocol changes are requested on an amendment application available on the IRB web site; please reference your IRB number and attach any documents that are being amended.

STUDY COMPLETION: The completion of a study must be reported to the IRB within 14 days.

Thank you for your cooperation in our shared efforts to assure that the rights and welfare of people participating in research are protected.

Tracy Cromp, M.S.W.
Director

DEPT: Sociology, 314 Lyman Hall **STUDENT**: Natalee Simpson

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APPENDIX E: SPSS OUTPUT - PRINCIPAL COMPONENT ANALYSIS

CORRELATION MATRIX

		Children have a right to know how they were conceived	Nondisclosure is the best way to avoid shame and stigma	Parents should wait for the child to ask	Disclosure will negatively impact the parent-child relationship	Health-care professionals should be informed of patients conception history	Disclosure is more difficult when there is a donor involved	One will know when the time is right to disclose	Families treat children poorly when they know the child was not conceived naturally	Disclosure threatens children's sense of identity	Disclosure leads to stigmatization	Having a support network makes disclosure less painful	Disclosure is the best way to protect the child from accidental discovery	Nondisclosure is the best way to protect the child	People are generally judgmental towards individuals who use medical assistance to conceive	The use of reproductive technology is a private matter	Parents and children are 'co-owners' of their conception story	Health practitioners should be required to provide resources to assist with disclosure	Disclosure is a way to demonstrate to the child how much they are wanted
Correlation	Children have a right to know how they were conceived	1.000	-.349	-.273	-.157	.081	-.223	-.252	.074	-.239	-.275	.174	.299	-.382	-.025	-.161	.443	.095	.227
	Nondisclosure is the best way to avoid shame and stigma	-.349	1.000	.138	.135	-.057	.409	.133	.132	.300	.312	-.151	-.189	.425	.230	.349	-.339	.016	-.099
	Parents should wait for the child to ask	-.273	.138	1.000	.240	-.035	.174	.298	-.012	.191	.144	-.177	-.308	.283	-.003	.104	-.128	-.043	-.194
	Disclosure will negatively impact the parent-child relationship	-.157	.135	.240	1.000	.024	.195	.058	.231	.491	.346	.097	.053	.190	.139	.076	-.031	.213	.045
	Health-care professionals should be informed of patients conception history	.081	-.057	-.035	.024	1.000	.051	-.039	-.084	.030	-.039	.237	.103	.000	-.079	.039	.188	.348	.138
	Disclosure is more difficult when there is a donor involved	-.223	.409	.174	.195	.051	1.000	.129	.059	.216	.307	.044	-.148	.188	.309	.356	-.216	.107	.166
	One will know when the time is right to disclose	-.252	.133	.298	.058	-.039	.129	1.000	-.098	.143	.149	-.044	-.050	.106	-.079	.055	-.171	.000	.031
	Families treat children poorly when they know the child was not conceived naturally	.074	.132	-.012	.231	-.084	.059	-.098	1.000	.256	.396	.110	.116	-.106	.250	.067	-.022	.063	.031
	Disclosure threatens children's sense of identity	-.239	.300	.191	.491	.030	.216	.143	.256	1.000	.628	.135	.015	.262	.243	.175	-.121	.264	-.082
	Disclosure leads to stigmatization	-.275	.312	.144	.346	-.039	.307	.149	.396	.628	1.000	.195	.001	.270	.407	.140	-.181	.151	-.027
	Having a support network makes disclosure less painful	.174	-.151	-.177	.097	.237	.044	-.044	.110	.135	.195	1.000	.352	-.152	.050	.002	-.021	.346	.312
	Disclosure is the best way to protect the child from accidental discovery	.299	-.189	-.308	.053	.103	-.148	-.050	.116	.015	.001	.352	1.000	-.330	.073	-.126	.225	.202	.395
	Nondisclosure is the best way to protect the child	-.382	.425	.283	.190	.000	.188	.106	-.106	.262	.270	-.152	-.330	1.000	.020	-.008	-.302	-.008	-.117
	People are generally judgmental towards individuals who use medical assistance to conceive	-.025	.230	-.003	.139	-.079	.309	-.079	.250	.243	.407	.050	.073	.020	1.000	.186	-.065	.111	.137
	The use of reproductive technology is a private matter	-.161	.349	.104	.076	.039	.356	.055	.067	.175	.140	.002	-.126	-.008	.186	1.000	-.149	-.024	-.093
	Parents and children are 'co-owners' of their conception story	.443	-.339	-.128	-.031	.188	-.216	-.171	-.022	-.121	-.181	-.021	.225	-.302	-.065	-.149	1.000	.291	.267
	Health practitioners should be required to provide resources to assist with disclosure	.095	.016	-.043	.213	.348	.107	.000	.063	.264	.151	.346	.202	-.008	.111	-.024	.291	1.000	.319
	Disclosure is a way to demonstrate to the child how much they are wanted	.227	-.099	-.194	.045	.138	.166	.031	.031	-.082	-.027	.312	.395	-.117	.137	-.093	.267	.319	1.000

COMMUNALITIES

	Initial	Extraction
Children have a right to know how they were conceived	1.000	.579
Nondisclosure is the best way to avoid shame and stigma	1.000	.591
Parents should wait for the child to ask	1.000	.647
Disclosure will negatively impact the parent-child relationship	1.000	.551
Health-care professionals should be informed of patients conception history	1.000	.634
Disclosure is more difficult when there is a donor involved	1.000	.669
One will know when the time is right to disclose	1.000	.759
Families treat children poorly when they know the child was not conceived naturally	1.000	.581
Disclosure threatens children's sense of identity	1.000	.696
Disclosure leads to stigmatization	1.000	.712
Having a support network makes disclosure less painful	1.000	.645
Disclosure is the best way to protect the child from accidental discovery	1.000	.607
Nondisclosure is the best way to protect the child	1.000	.576
People are generally judgmental towards individuals who use medical assistance to conceive	1.000	.543
The use of reproductive technology is a private matter	1.000	.524
Parents and children are 'co-owners' of their conception story	1.000	.751
Health practitioners should be required to provide resources to assist with disclosure	1.000	.646
Disclosure is a way to demonstrate to the child how much they are wanted	1.000	.616

Extraction Method: Principal Component Analysis.

COMPONENT MATRIX

	Component					
	1	2	3	4	5	6
Nondisclosure is the best way to avoid shame and stigma	.677			.327		
Disclosure leads to stigmatization	.657	.429				
Children have a right to know how they were conceived	-.631					
Disclosure threatens children's sense of identity	.627	.418		-.343		
Nondisclosure is the best way to protect the child	.578		.308			-.312
Disclosure is more difficult when there is a donor involved	.548			.537		
Parents and children are 'co-owners' of their conception story	-.521	.314			.468	.350
Parents should wait for the child to ask	.464		.336			.443
Disclosure will negatively impact the parent-child relationship	.444	.383		-.401		
Health practitioners should be required to provide resources to assist with disclosure		.646	.429			
Having a support network makes disclosure less painful		.618			-.355	-.326
Disclosure is the best way to protect the child from accidental discovery	-.370	.572			-.363	
Disclosure is a way to demonstrate to the child how much they are wanted		.561		.308		
Health-care professionals should be informed of patients conception history		.327	.545			
Families treat children poorly when they know the child was not conceived naturally		.405	-.527			
People are generally judgmental towards individuals who use medical assistance to conceive	.346	.393	-.440			
The use of reproductive technology is a private matter	.397			.520		
One will know when the time is right to disclose	.309		.387		-.529	.472

Extraction Method: Principal Component Analysis.

a. 6 components extracted.

PRINCIPAL COMPONENT ANALYSIS – TWO FACTOR EXTRACTION

COMMUNALITIES

	Initial	Extraction
Children have a right to know how they were conceived	1.000	.482
Nondisclosure is the best way to avoid shame and stigma	1.000	.460
Parents should wait for the child to ask	1.000	.264
Disclosure will negatively impact the parent-child relationship	1.000	.343
Health-care professionals should be informed of patients conception history	1.000	.121
Disclosure is more difficult when there is a donor involved	1.000	.342
One will know when the time is right to disclose	1.000	.105
Families treat children poorly when they know the child was not conceived naturally	1.000	.211
Disclosure threatens children's sense of identity	1.000	.568
Disclosure leads to stigmatization	1.000	.616
Having a support network makes disclosure less painful	1.000	.394
Disclosure is the best way to protect the child from accidental discovery	1.000	.464
Nondisclosure is the best way to protect the child	1.000	.375
People are generally judgmental towards individuals who use medical assistance to conceive	1.000	.274
The use of reproductive technology is a private matter	1.000	.160
Parents and children are 'co-owners' of their conception story	1.000	.370
Health practitioners should be required to provide resources to assist with disclosure	1.000	.418
Disclosure is a way to demonstrate to the child how much they are wanted	1.000	.373

Extraction Method: Principal Component Analysis.

COMPONENT MATRIX

	Component	
	1	2
Nondisclosure is the best way to avoid shame and stigma	.677	
Disclosure leads to stigmatization	.657	.429
Children have a right to know how they were conceived	-.631	
Disclosure threatens children's sense of identity	.627	.418
Nondisclosure is the best way to protect the child	.578	
Disclosure is more difficult when there is a donor involved	.548	
Parents and children are 'co-owners' of their conception story	-.521	.314
Parents should wait for the child to ask	.464	
Disclosure will negatively impact the parent-child relationship	.444	.383
The use of reproductive technology is a private matter	.397	
One will know when the time is right to disclose	.309	
Health practitioners should be required to provide resources to assist with disclosure		.646
Having a support network makes disclosure less painful		.618
Disclosure is the best way to protect the child from accidental discovery	-.370	.572
Disclosure is a way to demonstrate to the child how much they are wanted		.561
Families treat children poorly when they know the child was not conceived naturally		.405
People are generally judgmental towards individuals who use medical assistance to conceive	.346	.393
Health-care professionals should be informed of patients conception history		.327

Extraction Method: Principal Component Analysis.
a. 2 components extracted.

PATTERN MATRIX

	Component	
	1	2
Disclosure leads to stigmatization	.785	
Disclosure threatens children's sense of identity	.754	
Disclosure will negatively impact the parent-child relationship	.587	
Disclosure is more difficult when there is a donor involved	.561	
Nondisclosure is the best way to avoid shame and stigma	.521	-.395
People are generally judgmental towards individuals who use medical assistance to conceive	.515	
Families treat children poorly when they know the child was not conceived naturally	.420	
The use of reproductive technology is a private matter	.345	
Disclosure is the best way to protect the child from accidental discovery		.683
Disclosure is a way to demonstrate to the child how much they are wanted		.603
Children have a right to know how they were conceived	-.324	.589
Having a support network makes disclosure less painful		.580
Parents and children are 'co-owners' of their conception story		.549
Health practitioners should be required to provide resources to assist with disclosure	.397	.542
Nondisclosure is the best way to protect the child	.336	-.486
Parents should wait for the child to ask		-.440
Health-care professionals should be informed of patients conception history		.340
One will know when the time is right to disclose		

Extraction Method: Principal Component Analysis.
a. Rotation converged in 33 iterations.

STRUCTURE MATRIX

	Component	
	1	2
Disclosure leads to stigmatization	.785	
Disclosure threatens children's sense of identity	.753	
Disclosure will negatively impact the parent-child relationship	.581	
Disclosure is more difficult when there is a donor involved	.571	
Nondisclosure is the best way to avoid shame and stigma	.552	-.435
People are generally judgmental towards individuals who use medical assistance to conceive	.504	
Families treat children poorly when they know the child was not conceived naturally	.403	
The use of reproductive technology is a private matter	.359	
Disclosure is the best way to protect the child from accidental discovery		.679
Children have a right to know how they were conceived	-.370	.615
Disclosure is a way to demonstrate to the child how much they are wanted		.591
Parents and children are 'co-owners' of their conception story		.567
Having a support network makes disclosure less painful		.558
Nondisclosure is the best way to protect the child	.374	-.513
Health practitioners should be required to provide resources to assist with disclosure	.354	.511
Parents should wait for the child to ask		-.458
Health-care professionals should be informed of patients conception history		.331
One will know when the time is right to disclose		

Extraction Method: Principal Component Analysis.

COMPONENT CORRELATION MATRIX

Component	1	2
1	1.000	-.078
2	-.078	1.000

Extraction Method: Principal Component

VARIMAX ROTATION FOR UNCORRELATED FACTORS

COMMUNALITIES

	Initial	Extraction
Children have a right to know how they were conceived	1.000	.579
Nondisclosure is the best way to avoid shame and stigma	1.000	.591
Parents should wait for the child to ask	1.000	.647
Disclosure will negatively impact the parent-child relationship	1.000	.551
Health-care professionals should be informed of patients conception history	1.000	.634
Disclosure is more difficult when there is a donor involved	1.000	.669
One will know when the time is right to disclose	1.000	.759
Families treat children poorly when they know the child was not conceived naturally	1.000	.581
Disclosure threatens children's sense of identity	1.000	.696
Disclosure leads to stigmatization	1.000	.712
Having a support network makes disclosure less painful	1.000	.645
Disclosure is the best way to protect the child from accidental discovery	1.000	.607
Nondisclosure is the best way to protect the child	1.000	.576
People are generally judgmental towards individuals who use medical assistance to conceive	1.000	.543
The use of reproductive technology is a private matter	1.000	.524
Parents and children are 'co-owners' of their conception story	1.000	.751
Health practitioners should be required to provide resources to assist with disclosure	1.000	.646
Disclosure is a way to demonstrate to the child how much they are wanted	1.000	.616

Extraction Method: Principal Component Analysis.

ROTATED COMPONENT MATRIX

	Component					
	1	2	3	4	5	6
Disclosure threatens children's sense of identity	.772					
Disclosure leads to stigmatization	.748					
Disclosure will negatively impact the parent-child relationship	.686					
Families treat children poorly when they know the child was not conceived naturally	.621					
Parents and children are 'co-owners' of their conception story		.788			.328	
Children have a right to know how they were conceived		.662				
Nondisclosure is the best way to protect the child		-.609	-.314			
Having a support network makes disclosure less painful			.718			
Disclosure is the best way to protect the child from accidental discovery			.705			
Disclosure is a way to demonstrate to the child how much they are wanted		.310	.619			
Disclosure is more difficult when there is a donor involved				.754		
The use of reproductive technology is a private matter				.711		
Nondisclosure is the best way to avoid shame and stigma		-.457		.570		
People are generally judgmental towards individuals who use medical assistance to conceive	.385			.558		
Health-care professionals should be informed of patients conception history					.779	
Health practitioners should be required to provide resources to assist with disclosure					.672	
One will know when the time is right to disclose						.835
Parents should wait for the child to ask			-.485			.587

Extraction Method: Principal Component Analysis.

a. Rotation converged in 8 iterations.

COMPONENT TRANSFORMATION MATRIX

Component	1	2	3	4	5	6
1	.548	-.582	-.267	.476	-.031	.250
2	.549	.312	.648	.186	.371	-.094
3	-.189	-.154	-.057	-.239	.765	.544
4	-.586	-.071	.213	.760	.152	-.081
5	.137	.401	-.664	.201	.417	-.406
6	.037	.612	-.138	.253	-.282	.679

Extraction Method: Principal Component Analysis.

PRINCIPAL COMPONENT ANALYSIS – TWO FACTOR EXTRACTION (VARIMAX ROTATION)

COMMUNALITIES

	Initial	Extraction
Children have a right to know how they were conceived	1.000	.482
Nondisclosure is the best way to avoid shame and stigma	1.000	.460
Parents should wait for the child to ask	1.000	.264
Disclosure will negatively impact the parent-child relationship	1.000	.343
Health-care professionals should be informed of patients conception history	1.000	.121
Disclosure is more difficult when there is a donor involved	1.000	.342
One will know when the time is right to disclose	1.000	.105
Families treat children poorly when they know the child was not conceived naturally	1.000	.211
Disclosure threatens children's sense of identity	1.000	.568
Disclosure leads to stigmatization	1.000	.616
Having a support network makes disclosure less painful	1.000	.394
Disclosure is the best way to protect the child from accidental discovery	1.000	.464
Nondisclosure is the best way to protect the child	1.000	.375
People are generally judgmental towards individuals who use medical assistance to conceive	1.000	.274
The use of reproductive technology is a private matter	1.000	.160
Parents and children are 'co-owners' of their conception story	1.000	.370
Health practitioners should be required to provide resources to assist with disclosure	1.000	.418
Disclosure is a way to demonstrate to the child how much they are wanted	1.000	.373

Extraction Method: Principal Component Analysis.

COMPONENT MATRIX

	Component	
	1	2
Nondisclosure is the best way to avoid shame and stigma	.677	
Disclosure leads to stigmatization	.657	.429
Children have a right to know how they were conceived	-.631	
Disclosure threatens children's sense of identity	.627	.418
Nondisclosure is the best way to protect the child	.578	
Disclosure is more difficult when there is a donor involved	.548	
Parents and children are 'co-owners' of their conception story	-.521	.314
Parents should wait for the child to ask	.464	
Disclosure will negatively impact the parent-child relationship	.444	.383
The use of reproductive technology is a private matter	.397	
One will know when the time is right to disclose	.309	
Health practitioners should be required to provide resources to assist with disclosure		.646
Having a support network makes disclosure less painful		.618
Disclosure is the best way to protect the child from accidental discovery	-.370	.572
Disclosure is a way to demonstrate to the child how much they are wanted		.561
Families treat children poorly when they know the child was not conceived naturally		.405
People are generally judgmental towards individuals who use medical assistance to conceive	.346	.393
Health-care professionals should be informed of patients conception history		.327

Extraction Method: Principal Component Analysis.
a. 2 components extracted.

ROTATED COMPONENT MATRIX

	Component	
	1	2
Disclosure leads to stigmatization	.783	
Disclosure threatens children's sense of identity	.752	
Disclosure will negatively impact the parent-child relationship	.584	
Disclosure is more difficult when there is a donor involved	.562	
Nondisclosure is the best way to avoid shame and stigma	.526	-.427
People are generally judgmental towards individuals who use medical	.512	
Families treat children poorly when they know the child was not conceived naturally	.416	
The use of reproductive technology is a private matter	.347	
Disclosure is the best way to protect the child from accidental discovery		.680
Children have a right to know how they were conceived	-.332	.610
Disclosure is a way to demonstrate to the child how much they are wanted		.594
Parents and children are 'co-owners' of their conception story		.563
Having a support network makes disclosure less painful		.562
Health practitioners should be required to provide resources to assist with disclosure	.388	.517
Nondisclosure is the best way to protect the child	.343	-.507
Parents should wait for the child to ask		-.454
Health-care professionals should be informed of patients conception history		.333
One will know when the time is right to disclose		

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.

COMPONENT TRANSFORMATION MATRIX

Component	1	2
1	.802	-.598
2	.598	.802

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

APPENDIX G:

SPSS RELIABILITY ANALYSES RESULTS FOR DEVELOPMENT OF SCALES

FEAR MOTIVATED NON-DISCLOSURE

Reliability Statistics for Fear Motivated Non-Disclosure

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.708	.713	7

Item Statistics for Fear Motivated Non-Disclosure

	Mean	Std. Deviation	N
Disclosure leads to stigmatization	1.88	.962	104
Disclosure threatens children's sense of identity	1.70	.858	104
Disclosure will negatively impact the parent-child relationship	1.51	.668	104
Disclosure is more difficult when there is a donor involved	3.60	1.075	104
People are generally judgmental towards individuals who use medical assistance to conceive	2.60	1.170	104
Families treat children poorly when they know the child was not conceived naturally	1.63	.827	104
The use of reproductive technology is a private matter	3.79	.867	104

Inter-Item Correlation Matrix for Fear Motivated Non-Disclosure

	Disclosure leads to stigmatization	Disclosure threatens children's sense of identity	Disclosure will negatively impact the parent-child relationship	Disclosure is more difficult when there is a donor involved	People are generally judgmental towards individuals who use medical assistance to conceive	Families treat children poorly when they know the child was not conceived naturally	The use of reproductive technology is a private matter
Disclosure leads to stigmatization	1.000	.625	.342	.307	.412	.392	.154
Disclosure threatens children's sense of identity	.625	1.000	.488	.216	.247	.252	.189
Disclosure will negatively impact the parent-child relationship	.342	.488	1.000	.195	.142	.226	.087
Disclosure is more difficult when there is a donor involved	.307	.216	.195	1.000	.309	.057	.356
People are generally judgmental towards individuals who use medical assistance to conceive	.412	.247	.142	.309	1.000	.253	.183
Families treat children poorly when they know the child was not conceived naturally	.392	.252	.226	.057	.253	1.000	.078
The use of reproductive technology is a private matter	.154	.189	.087	.356	.183	.078	1.000

Item-Total Statistics for Fear Motivated Non-Disclosure

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Disclosure leads to stigmatization	14.82	10.597	.625	.514	.618
Disclosure threatens children's sense of identity	14.99	11.582	.535	.485	.648
Disclosure will negatively impact the parent-child relationship	15.18	13.141	.382	.260	.687
Disclosure is more difficult when there is a donor involved	13.10	11.428	.393	.237	.684
People are generally judgmental towards individuals who use medical assistance to conceive	14.10	10.787	.427	.224	.677
Families treat children poorly when they know the child was not conceived naturally	15.07	12.821	.327	.186	.696
The use of reproductive technology is a private matter	12.90	12.903	.287	.148	.706

CARE MOTIVATED DISCLOSURE

SIX ITEMS INCLUDED IN RELIABILITY ANALYSIS:

Reliability Statistics for Care Motivated Disclosure

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.603	.606	6

Item Statistics for Care Motivated Disclosure

	Mean	Std. Deviation	N
Disclosure is the best way to protect the child from accidental discovery	4.0096	.95017	104
Disclosure is a way to demonstrate to the child how much they are wanted	3.7885	1.03973	104
Having a support network makes disclosure less painful	3.9615	.90224	104
Parents and children are 'co-owners' of their conception story	3.7500	1.06807	104
Parents should wait for the child to ask	3.8173	.86759	104
Health-care professionals should be informed of patients conception history	3.6442	1.02321	104

Inter-Item Correlation Matrix for Care Motivated Disclosure

	Disclosure is the best way to protect the child from accidental discovery	Disclosure is a way to demonstrate to the child how much they are wanted	Having a support network makes disclosure less painful	Parents and children are 'co-owners' of their conception story	Parents should wait for the child to ask	Health-care professionals should be informed of patients conception history
Disclosure is the best way to protect the child from accidental discovery	1.000	.395	.352	.232	.308	.103
Disclosure is a way to demonstrate to the child how much they are wanted	.395	1.000	.312	.267	.194	.138
Having a support network makes disclosure less painful	.352	.312	1.000	-.020	.177	.237
Parents and children are 'co-owners' of their conception story	.232	.267	-.020	1.000	.128	.202
Parents should wait for the child to ask	.308	.194	.177	.128	1.000	.035
Health-care professionals should be informed of patients conception history	.103	.138	.237	.202	.035	1.000

Item-Total Statistics for Care Motivated Disclosure

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Disclosure is the best way to protect the child from accidental discovery	18.9615	8.076	.475	.277	.502
Disclosure is a way to demonstrate to the child how much they are wanted	19.1827	7.860	.446	.234	.509
Having a support network makes disclosure less painful	19.0096	8.864	.347	.228	.556
Parents and children are 'co-owners' of their conception story	19.2212	8.698	.270	.153	.589
Parents should wait for the child to ask	19.1538	9.355	.270	.108	.584
Health-care professionals should be informed of patients conception history	19.3269	9.057	.234	.101	.603

FIVE ITEMS INCLUDED IN RELIABILITY ANALYSIS:

Reliability Statistics for Care Motivated Disclosure

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.603	.605	5

Item Statistics for Care Motivated Disclosure

	Mean	Std. Deviation	N
Disclosure is the best way to protect the child from accidental discovery	4.0096	.95017	104
Disclosure is a way to demonstrate to the child how much they are wanted	3.7885	1.03973	104
Having a support network makes disclosure less painful	3.9615	.90224	104
Parents and children are 'co-owners' of their conception story	3.7500	1.06807	104
Parents should wait for the child to ask	3.8173	.86759	104

Inter-Item Correlation Matrix for Care Motivated Disclosure

	Disclosure is the best way to protect the child from accidental discovery	Disclosure is a way to demonstrate to the child how much they are wanted	Having a support network makes disclosure less painful	Parents and children are 'co-owners' of their conception story	Parents should wait for the child to ask
Disclosure is the best way to protect the child from accidental discovery	1.000	.395	.352	.232	.308
Disclosure is a way to demonstrate to the child how much they are wanted	.395	1.000	.312	.267	.194
Having a support network makes disclosure less painful	.352	.312	1.000	-.020	.177
Parents and children are 'co-owners' of their conception story	.232	.267	-.020	1.000	.128
Parents should wait for the child to ask	.308	.194	.177	.128	1.000

Item-Total Statistics for Care Motivated Disclosure

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Disclosure is the best way to protect the child from accidental discovery	15.3173	5.792	.517	.277	.461
Disclosure is a way to demonstrate to the child how much they are wanted	15.5385	5.668	.466	.233	.484
Having a support network makes disclosure less painful	15.3654	6.817	.303	.184	.575
Parents and children are 'co-owners' of their conception story	15.5769	6.654	.229	.115	.622
Parents should wait for the child to ask	15.5096	6.932	.300	.108	.576

FOUR ITEMS INCLUDED IN RELIABILITY ANALYSIS:

Reliability Statistics for Care Motivated Disclosure

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.622	.620	4

Item Statistics for Care Motivated Disclosure

	Mean	Std. Deviation	N
Disclosure is the best way to protect the child from accidental discovery	4.0096	.95017	104
Disclosure is a way to demonstrate to the child how much they are wanted	3.7885	1.03973	104
Having a support network makes disclosure less painful	3.9615	.90224	104
Parents should wait for the child to ask	3.8173	.86759	104

Inter-Item Correlation Matrix for Care Motivated Disclosure

	Disclosure is the best way to protect the child from accidental discovery	Disclosure is a way to demonstrate to the child how much they are wanted	Having a support network makes disclosure less painful	Parents should wait for the child to ask
Disclosure is the best way to protect the child from accidental discovery	1.000	.395	.352	.308
Disclosure is a way to demonstrate to the child how much they are wanted	.395	1.000	.312	.194
Having a support network makes disclosure less painful	.352	.312	1.000	.177
Parents should wait for the child to ask	.308	.194	.177	1.000

Item-Total Statistics for Care Motivated Disclosure

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Disclosure is the best way to protect the child from accidental discovery	11.5673	3.860	.507	.257	.471
Disclosure is a way to demonstrate to the child how much they are wanted	11.7885	3.858	.420	.194	.540
Having a support network makes disclosure less painful	11.6154	4.375	.388	.162	.562
Parents should wait for the child to ask	11.7596	4.767	.299	.105	.620

APPENDIX H:

SUPPLEMENTAL CHI-SQUARE ANALYSES BETWEEN ITEMS ON THE FEAR MOTIVATED NON-DISCLOSURE SCALE[17]

Crosstabulation: Disclosure leads to stigmatization BY Sexual Identity

			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
GENERAL ATTITUDES TOWARDS DISCLOSURE ABOUT THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY TO CONCEIVE-Disclosure leads to stigmatization	Strongly Disagree	Count	34	11	45	2.915	4
		Sexual Identity	42.0%	45.8%	42.9%		
	Disagree	Count	28	11	39		
		Sexual Identity	34.6%	45.8%	37.1%		
	Neither Agree nor Disagree	Count	11	1	12		
		Sexual Identity	13.6%	4.2%	11.4%		
	Agree	Count	7	1	8		
		Sexual Identity	8.6%	4.2%	7.6%		
	Strongly Agree	Count	1	0	1		
		Sexual Identity	1.2%	0.0%	1.0%		
Total		Count	81	24	105		
		Sexual Identity	100.0%	100.0%	100.0%		

Crosstabulation: Disclosure threatens children's sense of identity BY Sexual Identity

			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
GENERAL ATTITUDES TOWARDS DISCLOSURE ABOUT THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY TO CONCEIVE-Disclosure threatens children's sense of identity	Strongly Disagree	Count	40	15	55	2.078	3
		Sexual Identity	49.4%	62.5%	52.4%		
	Disagree	Count	25	6	31		
		Sexual Identity	30.9%	25.0%	29.5%		
	Neither Agree nor Disagree	Count	12	3	15		
		Sexual Identity	14.8%	12.5%	14.3%		
	Agree	Count	4	0	4		
		Sexual Identity	4.9%	0.0%	3.8%		
Total		Count	81	24	105		
		Sexual Identity	100.0%	100.0%	100.0%		

Crosstabulation: Disclosure will negatively impact the parent-child relationship BY Sexual Identity

			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
GENERAL ATTITUDES TOWARDS DISCLOSURE ABOUT THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY TO CONCEIVE-Disclosure will negatively impact the parent-child relationship	Strongly Disagree	Count	45	16	61	1.219	3
		Sexual Identity	55.6%	66.7%	58.1%		
	Disagree	Count	29	7	36		
		Sexual Identity	35.8%	29.2%	34.3%		
	Neither Agree nor Disagree	Count	6	1	7		
		Sexual Identity	7.4%	4.2%	6.7%		
	Agree	Count	1	0	1		
		Sexual Identity	1.2%	0.0%	1.0%		
Total		Count	81	24	105		
		Sexual Identity	100.0%	100.0%	100.0%		

[17] Cell counts exceed 20%, results should be cautiously examined.

Crosstabulation: Disclosure is more difficult when there is a donor involved BY Sexual Identity							
			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
GENERAL ATTITUDES TOWARDS DISCLOSURE ABOUT THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY TO CONCEIVE-Disclosure is more difficult when there is a donor involved	Strongly Disagree	Count	1	4	5	27.677***	4
		Sexual Identity	1.3%	16.0%	4.8%		
	Disagree	Count	4	7	11		
		Sexual Identity	5.0%	28.0%	10.5%		
	Neither Agree nor Disagree	Count	18	8	26		
		Sexual Identity	22.5%	32.0%	24.8%		
	Agree	Count	36	6	42		
		Sexual Identity	45.0%	24.0%	40.0%		
	Strongly Agree	Count	21	0	21		
		Sexual Identity	26.3%	0.0%	20.0%		
Total		Count	80	25	105		
		Sexual Identity	100.0%	100.0%	100.0%		

Crosstabulation: People are generally judgmental towards individuals who use medical assistance to conceive BY Sexual Identity							
			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
GENERAL ATTITUDES TOWARDS DISCLOSURE ABOUT THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY TO CONCEIVE-People are generally judgmental towards individuals who use medical assistance to conceive	Strongly Disagree	Count	13	6	19	2.272	4
		Sexual Identity	16.0%	25.0%	18.1%		
	Disagree	Count	26	9	35		
		Sexual Identity	32.1%	37.5%	33.3%		
	Neither Agree nor Disagree	Count	22	6	28		
		Sexual Identity	27.2%	25.0%	26.7%		
	Agree	Count	13	2	15		
		Sexual Identity	16.0%	8.3%	14.3%		
	Strongly Agree	Count	7	1	8		
		Sexual Identity	8.6%	4.2%	7.6%		
Total		Count	81	24	105		
		Sexual Identity	100.0%	100.0%	100.0%		

Crosstabulation: Families treat children poorly when they know the child was not conceived naturally BY Sexual Identity							
			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
GENERAL ATTITUDES TOWARDS DISCLOSURE ABOUT THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY TO CONCEIVE-Families treat children poorly when they know the child was not conceived naturally	Strongly Disagree	Count	47	11	58	5.268	4
		Sexual Identity	58.0%	44.0%	54.7%		
	Disagree	Count	24	10	34		
		Sexual Identity	29.6%	40.0%	32.1%		
	Neither Agree nor Disagree	Count	8	3	11		
		Sexual Identity	9.9%	12.0%	10.4%		
	Agree	Count	2	0	2		
		Sexual Identity	2.5%	0.0%	1.9%		
	Strongly Agree	Count	0	1	1		
		Sexual Identity	0.0%	4.0%	.9%		
Total		Count	81	25	106		
		Sexual Identity	100.0%	100.0%	100.0%		

Crosstabulation: The use of reproductive technology is a private matter BY Sexual Identity							
			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
GENERAL ATTITUDES TOWARDS DISCLOSURE ABOUT THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGY TO CONCEIVE-The use of reproductive technology is a private matter	Strongly Disagree	Count	0	1	1	10.921*	4
		Sexual Identity	0.0%	4.2%	1.0%		
	Disagree	Count	4	0	4		
		Sexual Identity	4.9%	0.0%	3.8%		
	Neither Agree nor Disagree	Count	24	10	34		
		Sexual Identity	29.6%	41.7%	32.4%		
	Agree	Count	30	12	42		
		Sexual Identity	37.0%	50.0%	40.0%		
	Strongly Agree	Count	23	1	24		
		Sexual Identity	28.4%	4.2%	22.9%		
Total		Count	81	24	105		
		Sexual Identity	100.0%	100.0%	100.0%		

CHI-SQUARE RESULTS BETWEEN SEXUAL IDENTITY AND WHETHER ONE HAS MET THE MEDICAL DEFINITION OF INFERTILITY OR RECEIVED A DIAGNOSIS

Crosstabulation: Was there ever a time when you were trying to get pregnant but did not conceive within 12 months? BY Sexual Identity

			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
Was there ever a time when you were trying to get pregnant but did not conceive within 12 months?	Yes	Count	74	14	88	8.169**	1
		Sexual Identity	83.1%	56.0%	77.2%		
	No	Count	15	11	26		
		Sexual Identity	16.9%	44.0%	22.8%		
Total		Count	89	25	114		
		Sexual Identity	100.0%	100.0%	100.0%		

Crosstabulation: Have you ever been diagnosed or treated for a medical condition that prevented you from having a child BY Sexual Identity

			Sexual Identity			X^2	*df*
			Heterosexual	LGBQ	Total		
Have you ever been diagnosed or treated for a medical condition that prevented you from having a child	Yes	Count	36	6	42	2.270	1
		Sexual Identity	40.4%	24.0%	36.8%		
	No	Count	53	19	72		
		Sexual Identity	59.6%	76.0%	63.2%		
Total		Count	89	25	114		
		Sexual Identity	100.0%	100.0%	100.0%		

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Thesis: "Demographic and Social Determinants of Income in Jamaica: An Analysis of Survey Data 2002"

2002 B.Sc. (Hons.) International Relations (major) & Psychology (minor)
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WORK EXPERIENCE

Part-time Instructor, Summer Session I - 2016
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SOC101-Introduction to Sociology

Teaching Assistant, August 2014-December 2015
Maxwell School, Syracuse University
MAX201-Quantitative Methods for Social Research

Part-time Instructor, Summer Session I - 2015
Department of Sociology, Syracuse University
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Research Assistant, August 2013-May 2014
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Part-time Instructor, Summer Session I - 2013
Department of Sociology, Syracuse University
SOC318-Introduction to Research

Teaching Assistant, August 2012-May 2013
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Research Assistant, August 2010-May 2012
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Statistician & Unit Head-Special Projects, September 2007-August 2010
The Statistical Institute of Jamaica (STATIN), Kingston, Jamaica

Part - Time Tutor, September 2005-August 2010
The University of the West Indies, Mona.
Statistical Computing-MSc. & PhD. Human Resource Management.

Part –Time Tutor, January-May 2006 & January – May 2007
Management Institute for National Development (MIND). Kingston, Jamaica
Introduction to Social Research

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Office of the Campus Principal
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Introduction to Social Research & Statistics

Receptionist, Mona Information Technology Services (MITS), 2002 - 2003
The University of the West Indies, Mona

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United Nations Education, Scientific & Cultural Organization (UNESCO), Kingston
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RESEARCH AND TEACHING INTERESTS

Medical Sociology	Sociology of the family
Sociology of Reproduction	LGBT Family
Social Demography	Research Methods

PUBLICATIONS

Wilmoth, Janet & Natalee Simpson. 2013. "Demographic Perspectives on Aging", pp. 199-221 (chapter 9) in *Gerontology: Perspectives and Issues* (4th Edition), Edited by Janet Wilmoth and Kenneth Ferraro. Springer Publishing Company, New York.

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CONFERENCE PRESENTATIONS

"Explicating Gender and Ambivalence in Intergenerational Relationships: Insights from Case Studies of Transgender Adult-Children," with Rebecca Wang, Carrie Elliott, Tre Wentling and Andrew S. London. (August 2015). Society for the Study of Social Problems (SSSP).

"Veteran Status, Gender, and Extramarital Sex: Results from the General Social Survey" *with Andrew London and Janet Wilmoth* (February 2014). Eastern Sociological Society.

"Sexual Identity and Risky Sexual Behavior among High School Students in New York City" (August 2013). American Sociological Association.

"Sexual Identity and Behavior: The Experience of Pregnancy among New York City Adolescents" *with Andrew London* (March 2013). Eastern Sociological Society.

"Demographic and Social Determinants of Income in Jamaica: An Analysis of Survey Data 2002" (November 2005)**.** 10th Annual Derek Gordon Conference, University of the West Indies.

INVITED PRESENTATION

"Gender transition and Intergenerational Relationships Across the Life Course" *with Carrie Elliot*, *Andrew London*, *Tre Wentling and Rebecca Wang* (April 2014). Colgate University Spring 2014 Brown Bag Series.

"Sexual Identity and Sexual Activity among High School Students in New York" (February 2014). Eastern Sociological Society.

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